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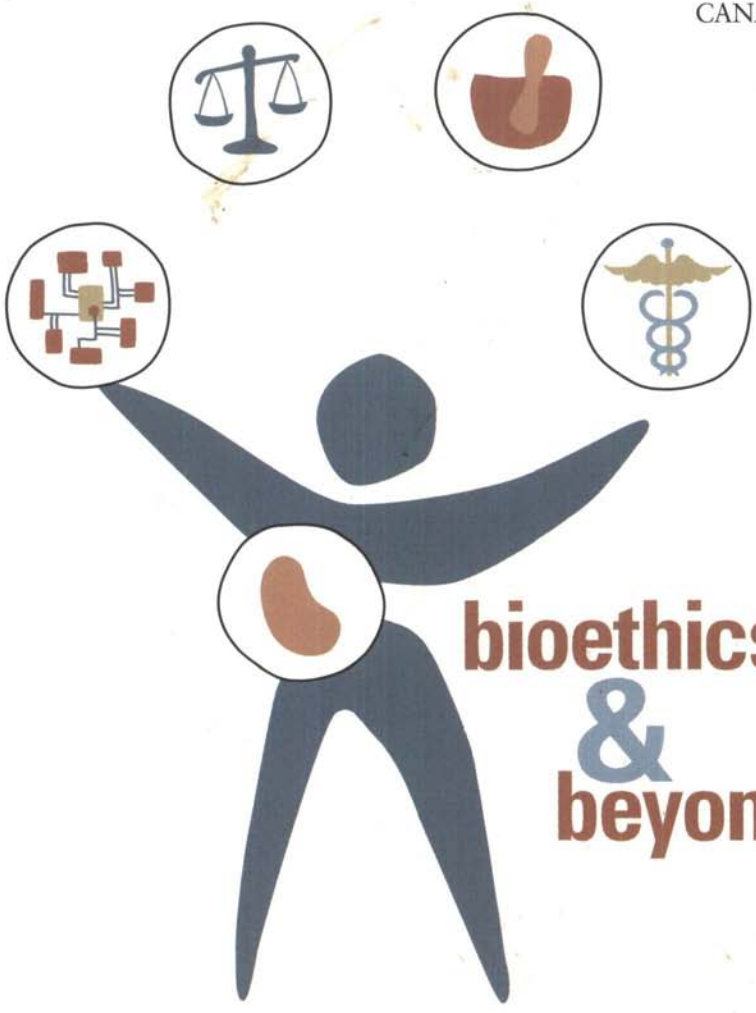

bioethics & beyond

Charles L. Bosk • Allan M. Brandt • Daniel Callahan
Alexander Morgan Capron • Nicholas A. Christakis
Larry R. Churchill • Lawrence Cohen • Norman Daniels
Veena Das • Renée C. Fox • Mary-Jo DelVecchio Good
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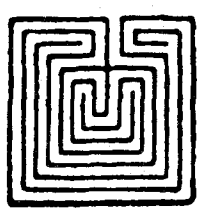

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Preface to the Issue "Bioethics and Beyond"

DÆDALUS, THE JOURNAL of the American Academy of Arts and Sciences, has on numerous occasions in the past launched studies of new disciplines, themes still in their infancy, showing signs of incontestable vigorous intellectual development. Bioethics joins the company of such pioneering issues whose origins are clearly American, having resonated originally for natural scientists, social scientists, and humanists in the United States, but having become important elsewhere in the world as well. In making such subjects "international," whether they have to do with arms control, experimentation with human subjects, the computer revolution, or social suffering—to give an illustration of many such efforts—a deliberate effort is made to reach out to secure foreign perspectives on what might otherwise be taken to be a purely American intellectual enterprise.

In all such issues, the cooperation of the Guest Editors is crucial. In this instance, it is a pleasure to recognize the efforts of Arthur Kleinman, Renée Fox, and Allan Brandt, whose planning did so much to bring this issue of *Dædalus* into being. Describing and analyzing the human condition—the perception

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that men and women have of themselves in this age of massive scientific and technological innovation—is not at all easy. If the biological and medical sciences are being perpetually transformed by new discovery, it is the interpretations of anthropologists, historians, sociologists, philosophers, lawyers, and others that make for a new appreciation of the values and beliefs that have now become common. To imagine that today there is a single-world society—a "global village" where all national identity is lost—is to believe that traditions are today largely extinct, that cultural and institutional differences have all but evaporated. Such is not the condition that informs the analyses of the authors who have written for this issue.

No one reading these pages can doubt that multidisciplinary and cross-cultural analysis provokes inquiry of a kind that is not possible when individuals are isolated in their specific intellectual disciplines. If one recognizes that there are, in the words of the Guest Editors, "plural ethics" operating in the world today, this has significance not only for those concerned with bioethics. That finding is relevant to much that divides the world today, that makes individuals perceive the most fundamental questions relating to the human condition in quite different ways.

We feel a deep gratitude to the Guest Editors and to all the authors who have written for this issue, who have sought to advance the study of bioethics.

S.R.G.

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Arthur Kleinman, Renée C. Fox, and Allan M. Brandt

Introduction

BIOLOGY AND BIOMEDICINE have achieved the status of cynosure in science and in the society of our era. They possess enormous cultural and commercial capital and are among the most visible and influential fields of our globalized world. It is not surprising, then, that the ethics of bioscience and biomedicine is also assuming unprecedented significance within institutions and among the general public. Major newspapers and weekly magazines continually feature stories and editorial commentary about thought-provoking, ethically problematic questions arising in medical laboratories, clinics, and the increasingly controversial arena of managed care. Questions of medical ethics are recurrently reported, animatedly discussed, and dramatized by the electronic media as well. Participants on television talk shows and radio call-in programs use terms like "patients' rights" and discuss moral and religious quandaries associated with biomedical advances with an ease and familiarity that did not exist thirty years ago. In just a few decades, ethics concerning health, illness, and medicine has moved from the social margins to the very center of societal debates, and a

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new field of inquiry and action focused on these matters has emerged—it is known as "bioethics."

The intent of this issue of *Dædalus* is to take a searching look at the phenomenon of bioethics—to examine what it is, where it has come from, where it seems to be headed, and, along with its achievements, limitations, and what it stands for and against, what its intended and unintended consequences are.

The perspectives that the contributing authors bring to bioethics, however, are oriented to a wider set of concerns with values in society, moral experience, and questions of meaning. They see "bioethics" as a developing field within the sphere of health, illness, and medicine that has a broad and deep social and cultural significance, with ramifications that go beyond bioethics. For them, "bioethics is not just bioethics."[1] Hence this issue's title: "Bioethics and Beyond."

Moral experiences in health and medicine have been bruited for centuries, seriously engaged in different epochs and societies by philosophers and religionists of various backgrounds as well as by physicians and nurses. But it was not until the late 1960s and early 1970s that a semiautonomous field concerned with the ethical implications of certain advances in biology and medicine, called bioethics, emerged—first in the United States and, subsequently, in numerous other countries. Although it is still in the process of defining itself and being defined, bioethics has become a more institutionalized and professionalized field over the course of its short history, with legitimated concepts, principles, and theories, methods of knowledge production, strategies for training and certifying experts, professional organizations and journals, and career pathways. Moreover, the field has "gone public." In the United States, its subject matter and concerns are not confined to the domains of medicine and academia; they are deliberated in the legislatures and courts of the land and frequently featured in the media, where "bioethicists" are called upon to be expert witnesses, consultants, and explicators.

The contributors to this issue of *Dædalus* recognize that despite a common core, bioethics has various manifestations and repercussions in different institutional, cultural, and societal contexts. They have brought their multidisciplinarity, their

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shared commitment to first-hand empirical research, and their cross-cultural and international outlook to bear upon these attributes of bioethics as well as upon a consideration of bioethics as a historical "happening." The essays in this volume range across the disciplines of philosophy, sociology, anthropology, medicine, public health, history, and law. They locate the practices of bioethics in their lived *contexts*—in an array of health-care, health-policy, medical-research, and medical-education settings, in a number of social and cultural milieux. These contexts, which are themselves undergoing changes, influenced by transformations in economy and polity, in science and technology, and in culture, shape bioethics and are in turn affected by it. The essays also move consideration of bioethics beyond its American beginnings, in ways that attempt to do more than highlight local traditions of relative moral common sense or criticize aseptic global bioethics theory. They point to the existence of a plural ethics currently operating in the world.

As readers of this volume will quickly discern, there are important and critical tensions across the diverse perspectives represented here. The idea of this collection was not to rehearse a long-standing debate between bioethics and its critics, but rather to deepen our understanding of the emergence of this field, to investigate its substantive intellectual and social orientations, as well as to speculate on future possibilities for inquiry and action at the critical sites of suffering and care. In this respect, the volume attempts to address the space between "is" and "ought," the territory typically experienced between the questions "what *is* the existing situation?" "what *should* be done about it?" and "what *can* be done?" As we look ahead, there is every reason to believe that the critical questions and conflicts reverberating through medicine in the form of ethical and moral quandaries will expand. On this point the essays reveal considerable consensus. Finding more creative ways of seeing, understanding, and adjudicating the values and beliefs in medicine will be an ongoing and critical process to which we hope this volume makes a modest contribution.

This issue of *Dædalus* has its origins in the W. H. R. Rivers Distinguished Lecture in the Department of Social Medicine at Harvard Medical School, delivered by Renée Fox on March 10,

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1998, and the workshop "Ethics, Medicine, and Social Science," funded by the department's Crichton fund, which featured most of the papers. A subsequent writers' conference at the Russell Sage Foundation facilitated the redrafting of papers and their preparation for publication. The participation of Walter Robinson, Judith Andre, Carl Elliott, and Barbara Koenig in the writers' conference contributed importantly to the reworking of the papers. The editors wish to thank the Russell Sage Foundation, the Greenwall Foundation, the Culpeper Foundation, the Commonwealth Fund, and the Michael Crichton Fund at Harvard Medical School for their financial support. They also thank Stephen Graubard for his assistance throughout the editorial process as well as Jennifer Nespole of the Russell Sage Foundation, and Joan Gillespie, Adriana Petryna, and Tripler Pell.

ENDNOTE

[1]Renée C. Fox and Judith P. Swazey, "Medical Morality Is Not Bioethics: Medical Ethics in China and the United States," *Perspectives in Biology and Medicine* 27 (4) (Spring 1984): 336–360.

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Renée C. Fox

Is Medical Education Asking Too Much of Bioethics?

TEACHING THE "NONBIOMEDICAL" ASPECTS OF MEDICINE: THE PERENNIAL PATTERN

AMERICAN MEDICAL EDUCATORS presently espouse, and are pedagogically committed to, the goal of fostering medical students' ability to integrate biomedical, social-scientific, and moral ways of perceiving, thinking, and understanding into the diagnostic, therapeutic, prognostic, and caring roles for which they are preparing a new generation of physicians. The majority of U.S. medical schools currently relies heavily on the relatively new, interdisciplinary field of bioethics to further this objective. Despite the fact that bioethics is only some thirty years old, both these patterns are associated with a century-long history of recurrent, markedly similar attempts to reform American medical education. The foci and leitmotifs of these attempts are articulated in the twenty-four reports advocating improvements in medical education successively issued since the publication of the famed 1910 Flexner Report, which radically altered medical education in the United States.[1] As physician and sociologist Nicholas A. Christakis has pointed out in a content analysis of these reports, every one of them proposed that the amount of "social science" offered in the curriculum be increased, though, as he observes, "what is considered to be 'social science' has changed over the years." For example, he notes in passing, "the early 1980s

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marked the emergence of the tendency to conflate medical ethics with the medical social sciences more generally."[2] Using a common vocabulary, the reports have repeatedly recommended that through the medium of such "non-biomedical fields," medical schools should augment their efforts to teach what are alternatively called the "behavioral," "social," "psychosocial," "humanistic," and "ethical" components of health and illness, of "knowing patients as persons," and of the character and comportment of "empathic," "healing" physicians. This proposal is also consistently linked with educating physicians to recognize and fulfill their larger professional responsibility to meet "community needs," "serve the public," and promote the "social good." The strikingly reiterative nature of the reports, in these (and other) respects, is partly related to a more general characteristic of American medical education—what sociologist Samuel W. Bloom has described as its history of "reform without change, of repeated modifications of the . . . curriculum that alter only very slightly or not at all the experience of the critical participants, the students and the teachers."[3]

Within this framework of perennial curriculum reform and little deep-structure change, medical educators have identified certain disciplines as vehicles of the "non-biomedical" intellectual and attitudinal training of medical students they aspire to effect. The principal fields they have designated for this role have varied over time. In the 1950s and the 1960s, for example, it was to psychiatry and the social sciences that medical educators accorded this task (in a period when social scientists who had obtained positions in medical schools were most likely to be affiliated with departments of psychiatry.) During the mid- to late 1960s community medicine acquired relatively short-lived prominence in this regard. And from the beginning of the 1970s to the present, it is bioethics that has come to be regarded as the foremost conveyor of other-than-biomedical learning to medical students.

The sequence involved here has been influenced by the state of these fields when they took on this medical educational assignment, and by the social climate that prevailed inside and outside the medical school during the particular decades in which they assumed it. In the post–World War II atmosphere of

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the 1950s into the 1960s psychoanalytically oriented psychiatry was at its height, and the social sciences were creatively flourishing. Both separately and collaboratively, these two fields were actively engaged in exploring the dynamic interplay of psychological, social, cultural, cross-cultural, and biological factors in health, illness, and care; in studying the experiences, feelings, and behavior of patients and families, doctors and nurses; in describing and analyzing the attributes and impact of the hospital (particularly the "mental hospital") as a social world; and in observing and delineating the socialization process through which medical students were progressively transmuted into physicians. It was principally around these kinds of materials that medical schools in these decades fashioned what they usually entitled behavioral-science courses. The 1960s ushered in a period of social ferment and protest, and of raised consciousness about individual and communal responsibility for participating in action to remedy some of the inequalities, injustice, and deprivation that violated basic American values. The florescence of community medicine in this era and its incorporation into the departmental organization as well as the curriculum of medical schools were catalyzed by this cultural mood. The emergence of bioethics at the inception of the 1970s, with its focus on problematic aspects of medical, scientific, and technological advances, its "neo-individualism" emphases, and its advertent and inadvertent involvement in questions of ultimate values and beliefs, coincided with medical and larger-than-medical developments taking place on the American scene.

Thus there is intellectual and historical logic, as well as "socio-logic," in the fact that medical educators have singled out certain disciplines to impart nonbiomedical knowledge and insights to medical students. However, the choices that have been made in this connection have not always been sufficiently informed. This is suggested by the tendency medical educators showed in the 1950s and 1960s to refer to all nonbiomedical subjects as social or behavioral science, and by their present inclination to lump them together under the label of bioethics. Such all-encompassing, nondifferentiated terms reveal a lack of clarity about the concepts, methods, ways of reasoning, and knowledge bases of the various nonbiomedical fields educators

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have drawn into the teaching of medical students, a disposition to regard them as interchangeable, and an inadequate, sometimes erroneous idea of the role these various disciplines can and cannot be expected to play in the education of future physicians. There is a sense in which medical educators have rather unreflectively seized upon one or another of these fields in a given decade, treating it as though it were an intellectual panacea for dealing with the difficulties of imparting more than strictly defined biomedicine to medical students.

And there have been difficulties in doing so—long-standing, chronic ones. It must be candidly admitted that this dimension of medical education has been persistently problematic, and often quite unsuccessful. The deficiencies in medical educators' knowledge of the nonbiomedical fields they invoke are part of the trouble. But more fundamental is the well-known epistemological split that runs like a fault line through modern Western medical thinking—epitomized by the dichotomous distinction that is made between what is biomedical and what is not. The latter category is defined more or less residually: it comprises everything that falls outside the physical and biological parameters of medicine, everything that is not regarded as medicine's "hard," "objective," authentically scientific, and essential core. In contrast, nonbiomedical variables and subjects are considered more "soft" and "subjective," less tangible and coherent. Despite the pious affirmations of medical educators and other medical spokespersons about the indispensability of these issues to the compassionately competent practice of medicine and to the profession's social covenant, these components of medicine are implicitly viewed as more peripheral and less important to the training and work of physicians than those that are deemed scientific.

This evaluative message is tacitly transmitted to medical students through the way that the teaching of nonbiomedical subjects is typically structured and organized. Most commonly, these aspects of their education are cordoned off—dissociated both from the medical-scientific knowledge that students learn and from their clinical training and experiences. Prototypically, whether called bioethics or behavioral science (or, sometimes, medical humanities), these materials are presented in a sepa-

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rate course, generally of short duration, given in the first or second pre-clinical year of the curriculum. Such a pattern runs directly counter to recommendations repeatedly made over the past sixty-five years in the series of reports on reforming American medical education, which have continually affirmed that the presentation of nonbiomedical subject matter and perspectives—as the 1932 Rappleye Commission Report of the Association of American Medical Colleges put it—"should be made a part of the regular instruction in clinical subjects, not as courses detached from the main body of medical knowledge."[4]

Most medical educators would contend that the nonbiomedical aspects of the medical-school curriculum are intimately and strategically connected with the psychological, social, and moral formation that medical students undergo in the course of the extensive, often arduous process of becoming physicians. Nevertheless, little systematic effort has been made to relate the planning of these facets of the curriculum to what students confront and experience in the series of pre-clinical and clinical settings through which they move during their four years of medical school, or to how this affects their attitudes, conduct, and conceptions of their future professional role. In their frequently cited article, "Ethics in a Short White Coat,"[5] Dimitri Christakis and Chris Feudtner have critically commented on this failure through their analysis of the way ethics is currently taught in many medical schools. The focus of the teaching, they contend, is on ethical issues and decisions faced by residents and practicing physicians, rather than on those encountered by students in their daily rounds. In Christakis's and Feudtner's opinion, it is "pedagogically skewed to emphasize different decisions that students will *not* make until much later in their careers, while largely ignoring the more subtle ethical decisions that they *do* make every day."[6] One of the unintended consequences of this skew, they report in a subsequent article, is that it ignores, and may even contribute to, the "erosion" of ethical principles and behavior that a substantial number of medical students attest they see in themselves and their classmates during their clinical clerkships.[7] The authors, and the students whom they interviewed, attribute what they term this "degradation" of principles to an array of emotional and social pres-

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sures to which they are subject in the stress-ridden, hierarchical environment of the hospital. Most notable among these are the desire, and "sometimes the coercion" that students say they feel, to "fit in with the team" and be a "team player," and their sense of being "powerless" novices and subordinates in instances where they witness, or are asked to assist with, actions performed by house staff or attending physicians that they deem unethical.

It is not easy to design courses that take into account such experiences and reactions to them. They are part of a latent, attitude-learning trajectory medical students jointly undergo, one that lies so deeply below the surface of the explicitly planned curriculum that it has been referred to as a "'hidden' curriculum."[8] How hidden it can be was brought home to me when, while preparing this essay, I chanced upon some field notes I made in the mid-1950s as a member of a team of sociologists who were conducting an extensive study of the education, training, and socialization of students in several U.S. medical schools.[9] In the course of an interview that I had conducted with a third-year medical student, he informed me that "the place where students spend [the] most time working out their concept of medical ethics is psychiatry." This was triggered by the lecture devoted to medical ethics in their first-year, third-trimester course in psychiatry, he said; but, he continued, it was mainly due to the fact that students felt that their psychiatrist-teachers were the kinds of physicians to whom they could entrust their questions about the ethically charged situations in which they found themselves—who would listen attentively to what they had to say and would respond with non-condemnatory sensitivity. "I think this is quite remarkable," the student commented, "and I even wonder if the medical school faculty realizes this is the course of events." (They did not.)

With this as background, I want to return to the present to examine the medical-educational implications of the paramount role that bioethics currently plays as the reigning nonbiomedical field in most U.S. medical schools. My analysis will be embedded in some reflections on the ethos, intellectual attributes, and societal significance of American bioethics;[10] the state of knowl-

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edge and clinical efficacy of modern Western medicine; the socialization of medical students; and the situation of American medical education at this end-of-the-twentieth-century juncture.

THE ASCENT OF BIOETHICS: ITS MEDICAL EDUCATIONAL IMPLICATIONS

The term "bioethics" (and also the word "ethicist") came into being toward the end of the 1960s, in connection with a multidisciplinary area of inquiry and action that emerged and took shape in the United States at that time.[11] From its outset, this new field has concentrated on a particular cluster of advances in biology and medicine, and on the actual and potential questions and quandaries to which these scientific, technological, and clinical developments, and the means of achieving them, have contributed. Abortion; assisted modes of reproduction; genetic screening, manipulation, and therapy; organ replacement (through organ transplantation and artificial organs); the deployment of the life-support and life-sustaining paraphernalia of modern medicine; euthanasia; the engagement of human subjects in medical research—all have been especially strong and consistent centers of bioethical interest and involvement. Cross-cutting and interrelating these concrete bioethical preoccupations have been the persistent metathemes of bioethics—principally, issues concerning life and death and human personhood, their definition and meaning, beginning and end; the virtues, limits, and dangers of vigorously intervening in the human condition to alleviate suffering, improve the quality of existence, and maintain life; and the just and equitable allocation of scarce and vital resources that are not only economic and technological, but also entail the distribution of living parts of self and others (that is, donated human organs), and of care and caring.

It is not to matters of everyday ethics, then, that bioethics has been primarily attentive. Nor are its leitmotifs strictly medical and ethical in nature. Rather, they have more general moral, social, and also religious connotations. It is more than a coincidence that bioethics first made its appearance in American

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society during a period of acute and ramifying social and cultural ferment—in the late 1960s and early 1970s, when the civil rights, women's, and peace movements were at their height. In the several decades since, the value and belief questions that bioethics has pursued have continued to parallel those with which the society has been grappling more broadly—albeit phrased in its own restrictively medicalized, ethicized, and secularized vocabulary. The most important indicators of the larger societal significance of bioethics are the two forms of public status it has attained: the continuous and prominent coverage of the topics, cases, and issues that it treats by the print and electronic media; and the escalating extent to which the state and federal legislatures and courts of the country (including the U.S. Congress and Supreme Court) have been involved in debating and deliberating on bioethical questions, and in rendering decisions about them.

As bioethics has evolved and become more professionalized and institutionalized, it has assumed a place of greater consequence in the academic programs of colleges, universities, nursing schools, and especially in the curricula of medical schools. Virtually all of the 124 U.S. medical schools now offer and require some course work in bioethics, to which cardinal "nonbiomedical" teaching significance is attached. In most medical schools, bioethics has replaced psychiatry, the social (behavioral) sciences, and community medicine in this regard. Psychiatry has become more biologically oriented and engrossed; both community medicine and the social sciences have disappeared from the organizational structure and the programs of many medical schools as attention to the social aspects and responsibilities of medicine has waned.

What are the medical-educational effects of these developments? The answer can best be approached through a closer consideration of the conceptual framework in which bioethics is usually taught, and of the phenomena that are, and are not included in its orbit. To begin with, the regnant paradigm of bioethics is a highly rational, formal, largely deductive mode of argumentation that draws upon a "relatively small set of concepts"[12]—chiefly, the principles of autonomy, beneficence, nonmaleficence, and justice, and the derived rules of truthful-

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ness, privacy, confidentiality, and faithfulness.[13] Often referred to as "principlism," and drawn largely from the Anglo-American tradition of analytic philosophy, this system of thought was brought to bioethics and made preeminent within it by its founding generation of philosophers, and reinforced by the scientific positivism of biologists and physicians, and the analytical jurisprudence of the lawyers who accompanied them.

The importance that bioethical thought attaches to a coolly rational mode of analysis focused on autonomy-of-self bends it away from detailed attention to the empirical contexts in which ethically relevant events occur, from how they are experienced, and from serious consideration of the play of both rational and nonrational social and cultural factors in moral life—including what sociologist Harold Garfinkel might have termed "good sociological reasons for bad bioethical outcomes."[14] Values that give weight to feelings and relatedness, to a self-transcending sense of solidarity with known and unknown others, to the community and the society, and to a special obligation to heed the plight of those who are disadvantaged and underserved, are overshadowed by what some bioethicists have critically referred to as the "autonomy unbounded" rationalism of the field's outlook.[15]

Not only is bioethics disposed to minimize the role of social and cultural factors and regard them as epiphenomena; it is also inclined to look upon their invocation with wariness. This stems in good part from the intellectual and moral commitment of bioethics to an Olympian ideal of universal ethical principles—sometimes called "common morality"—and from bioethicists' connected concern about succumbing to "local meanings," or what they term "cultural and ethical relativism." Universal ethical standards exist, philosopher-bioethicist Ruth Macklin declares, in the contemporaneous form of "human rights," which she defines as "rights that belong to all people, wherever they may dwell and whatever may be the political system or the cultural traditions of their country or region of the world."[16] Along with numerous other American bioethicists, she rejects the idea that "human rights is a Western invention, or that it is a form of ethical imperialism to impose that Western concept on cultures with a different tradition."[17]

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While acknowledging that such ethical principles "require interpretation when they are applied to particular social institutions, such as a health care system or the practice of medicine," and that "[i]n the particulars, there is ample room to tolerate cultural diversity,"[18] she nonetheless avers that the cultural espousal and societal implementation of human rights-based ethical universals constitute "moral progress."[19] This kind of "stance against relativism,"[20] bioethicists are inclined to believe, is a safeguard against dangerous forms of particularism that, as philosopher-bioethicist Daniel Callahan has written, can eventuate in "subservience to the interest of class and tribe, to our crowd, and the passions of the moment."[21] In their view it is also essential to what many bioethicists regard as one of the most crucial and difficult tasks of ethics: "to stand in judgment" on cultural precepts and social behaviors that "seem to be wrong, misguided, or evil."[22] The "against relativism" outlook of bioethics runs counter to the emphasis that the social sciences place on the importance of recognizing and respecting the significance and the tenacity of historical, cultural, and societal differences in values, beliefs, conduct, and world views. It is a basic source of strain between the two fields.

Still another characteristic of bioethics is its secular outlook, even though some of its founders and most esteemed participants have been theologians or religious ethicists. Questions of a religious nature—concerning human origins, identity, and destiny, the meaning of suffering, and the mysteries of life and death—continually arise in bioethics; but they are generally defined as inherently insoluble problems pertaining to personal and private beliefs falling outside the domain of bioethics, or, more characteristically, are translated and assimilated into the field's conceptions of ethics and the ethical. This is a complex phenomenon to which the religious backgrounds and histories of influential bioethicists have contributed, along with the rationalism, positivism, and individualism of the field's intellectual culture. On a more macro level, the fact that bioethical issues with religious connotations have been projected into the public domain and the polity of American society—a society that is religiously pluralistic, intent on avoiding acrimoniously divisive religious controversy, and pledged to uphold the con-

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stitutional tenet of maintaining separation between church and state—has exerted a major influence on the pattern of "screening out" the religious content of bioethics, or "reducing" it to ethics.

Impelled throughout the 1990s by criticisms of the mode of thought, the discourse, and the perspective of bioethics—coming as much from inside the field as from outside it—efforts have been made by scholars and professionals engaged in bioethics to alter its cognitive structure, its methodology, and its ethos. These efforts have centered on trying to break through the domination of the field by the abstract "principlism" of analytic philosophy, as well as by the primacy accorded an autonomous, self-determined conception of individualism and individual rights; on endeavoring to achieve greater rapprochement between the rather polarized notions of individualism and community, and of universalism and particularism, that characterize the intellectual and moral framework of bioethics; on attempting to incorporate other philosophical systems into the matrix of bioethical thought (notably, casuistry, phenomenology, pragmatism, virtue ethics, narrative ethics, and feminist philosophy); and on promoting firsthand ethnographic methods of inquiry as a way to bring bioethics closer to how ethical quandaries are situationally and humanly experienced. To date, however, relatively little change has occurred in the contours, content, style of thought, or the ideology of bioethics.

American bioethics is an intellectual and social endeavor of great importance, not only because of its relevance to the moral formation and edification of physicians, but also because, as I have written elsewhere, "Bioethics is not just bioethics . . . and [it] is more than medical. Using biology and medicine as a metaphorical language and a symbolic medium, bioethics deals . . . with nothing less than beliefs, values, and norms that are basic to our society, its cultural tradition, and its collective conscience."[23] Nevertheless, bioethics is not prone to inquire into the nature of its wider significance, or to teach about it. Nor does it usually deal with larger social and moral issues of medical significance—such as suffering and ill health caused by poverty, homelessness, prejudice and discrimination, or even what sociologist David Mechanic has called "the most glaring

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perversity of U.S. medicine"—the fact that more than forty-four million people have no health insurance and many more are underinsured, "despite expenditures that far exceed those of any other nation."[24] Throughout most of its history bioethics has been inclined to treat problems of access to health care as social issues rather than ethical ones—drawing and maintaining a sharp dichotomy between the two.[25] Quite recently, bioethics has begun to address some of the ethical problems posed by the rise of managed care in the United States. But thus far the ethics of physician-patient and physician-organization relationships in this setting have been emphasized with relatively little consideration given to the ethics of health-care organizations, or to the ethical ramifications of the dominant role that for-profit health organizations have come to play in the delivery of health care in the United States since the 1980s.

Bioethics has consistently concentrated on a specific set of moral quandaries and critical choices, and contemplated a narrow range of alternative courses of action. Characteristically, for example, when in the realm of what is called "clinical bioethics" it focuses on ethical issues that occur between physicians and patients at the bedside, it does so with sparse reference to their respective social and cultural backgrounds, their "lived lives," the psychodynamics of what transpires between them, and the social milieu of the hospital in which these doctor-patient encounters take place.

Identifying what bioethics is and is not helps to clarify what medical educators should and should not expect of it. If my analysis is valid, then bioethics—at least in its present form—is being asked to assume too much responsibility for defining the orientation, content, and scope of the nonbiomedical aspects of medical students' professional education and development.

INTEGRATING MEDICINE, ETHICS, AND SOCIAL SCIENCES IN THE MEDICAL-SCHOOL CURRICULUM

It makes sense to structure the teaching of the knowledge and skills, the attitudes and values integral to these dimensions of physicianhood around an ethics core. For, in common with

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other professions, medicine is concerned with human affairs that are of special moral and existential importance in the lives of individuals, and in what the French sociologist Émile Durkheim termed the "*vie sérieuse*" ("serious life") of a society. In the case of medicine, this entails nothing less than a palpable and intimate relationship to the human body and psyche; to "some of the most basic and transcendent aspects of the human condition"—birth, growth and development, sexuality, aging, mortality and death; and to the comedy and tragedy, joys and sorrows, suffering and solace, and the irreducible enigmas and mysteries of the human "story."[26] In the words of physician-scientist and humanist Leon Kass, what this requires "is a matter not only of mind and hand, but also of the heart, not only of intellect and skill, but also of character. . . . It is rooted in our moral nature."[27] Physicians are ideally expected to grapple with problems entrusted to them by patients in a way that serves not only those persons' individual needs and welfare, but also (to quote theologian James M. Gustafson) "the larger ends and purposes of human good."[28] In this sense being a physician is not just an occupation. It is—or at least it ought to be—a "calling" as well.

However appropriate it may be for the nonbiomedical education of medical students to be built around the ethical center of the physician's role and the moral foundations of the profession of medicine, a larger-than-bioethics conception of ethics is needed to foster the social, emotional, and moral competence and growth of doctors-in-training and their capacity to implement and "uphold their most noble values" in the various arenas of their professional lives.[29] As I envisage it, this would entail inserting the sort of bioethics-driven approach that currently prevails in American medical schools in a psychological and social framework of analysis grounded in cases germane to "the morality of ordinary [medical] practice,"[30] which also opens onto a wide historical, cultural, and societal perspective. Such a framework would neither evade the spiritual questions evoked by illness and suffering, nor minimize the role that nonrational factors play in our individual and collective existence. Social and cultural differences would be fully acknowledged, not subordinated either to the recognition of common

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human attributes, or to the articulation of universal principles. The bearing of the diverse personalities and social backgrounds of patients on their health, on their experiences with illness and the health-care system, on the relationships they do and do not form with physicians, and on their reactions to the processes of diagnosis, therapy, prognosis, and to the culture of medicine, would be stressed. Methodical attention would be paid to the largely latent process of professional socialization through which medical students pass—that is, to the learning of certain attitudes, sentiments, and behaviors that they undergo in synchrony with their acquisition of knowledge and skills—and to the intellectual, interpersonal, and situational sources and shapers of these dimensions of becoming a doctor. Contemporaneous events and developments taking place on the broader American scene that directly or indirectly affect the health-care sector of society would also be considered.

Translating this purview into a concrete curriculum is not a simple undertaking. It requires the establishment of a knowledgeable, integrated, and synergistic relationship between medicine, ethics, and social science, accompanied by a considered, data-based analysis of when and where in the trajectory of medical education and medical students' stage of development the teaching that it entails ought ideally to occur, in what form, and by whom. Too much of this teaching has been squeezed into the first two years of medical school where, in compressed bursts of time, it is carried out by a procession of instructors assigned to give no more than one or two lectures apiece. Too little of it has been located in the third and fourth years of medical school—when students are learning to think and work as physicians, and the instruction could thus emanate directly from the clinical experiences they are having. In addition, it would be advisable for medical educators to consider whether some of the foundational teaching of these aspects of health, illness, and medicine ought to be done *before* students enter medical school, while they are still in their college years, in an intellectual setting and on a schedule conducive to being contemplative about these matters. Based on my own long history of teaching premed undergraduates, I believe not only that this is an optimal time for such learning to begin, but also that

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medical educators would transmit a strong message about the importance they attach to it if they made some relevant undergraduate course work a requirement for admission to medical school.

TRAINING FOR UNCERTAINTY AND TRAINING FOR DETACHED CONCERN

More is called for than earnestness about emphasizing these components of educating physicians-to-be, or astuteness about how to blend them into the medical-school curriculum and teach them with intellectual clear-sightedness, clinical relevance, and sociopsychological timeliness. It is also essential that this be done with attunement and responsiveness to the issues medical students are facing that emanate from the scientific and clinical state of the field they are being prepared to enter. These issues are attitudinal and philosophical, as well as cognitive and practical in nature. As generations of medical students have testified, foremost among them is learning to recognize the abiding presence of uncertainty in medicine—uncertainty that exists both in spite of and because of the vast knowledge and powerful skills that medicine commands—and to deal with its daunting implications. In the view of physician and historian Kenneth Ludmerer, training physicians to handle uncertainty as they carry out their preventive, diagnostic, therapeutic, and prognostic work in medical practice is, and should be, a primary goal of medical education. It is a goal that he also characterizes as exceedingly difficult to achieve—one that he calls medical education's "most elusive ideal."[31]

From the outset of my involvement in firsthand research on the education and socialization of medical students during the 1950s, what I have termed the process of "training for uncertainty"[32] has seemed to me to be as basic and demanding as Ludmerer states—a challenging quintessence of becoming a physician and of practicing medicine. If anything, it has become even more important during the past few decades, as changes in medical science, technology, and practice, and the social and cultural conditions surrounding them, have contributed to the appearance of new manifestations of medical uncertainty—

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and, in some respects, have enhanced or complicated long-standing, older patterns of uncertainty.[33]

A momentous source of current medical uncertainty is the biological revolution that has resulted from the identification of the self-complementary double-helix structure of DNA, the ascendancy of the new molecular and cell biology with its genetic focus that this has brought in its wake, and the explosion of information and knowledge that has ensued. Despite the promise of these spectacular scientific developments for transforming the practice of medicine, and the high expectations that they have engendered in this regard, it is unclear when, how, to what extent, or even whether such progress will actually come to pass. Molecular genetic testing is in its infancy; none of the gene therapy undertaken has as yet succeeded; and a wide conceptual gap, still unbridged, exists between the molecular and genetic knowledge that has been produced and the organismic, pathophysiological level on which clinical medicine is practiced. The so-called emergence and reemergence of infectious disease that has become noteworthy since the appearance and pandemic spread of HIV/AIDS is another major source of both new and old medical uncertainty. The enhanced importance of prognosis in medical practice—to which the increased prevalence of chronic disease and its care, the development of medical technology to ascertain the *in utero* condition of the fetus or detect the possible occurrence of a genetics-borne disorder, bioethical emphasis on informed consent before treatment or experimentation, the development of hospice, and the growth of managed care have all contributed—confronts physicians with a plethora of uncertainties. These are engendered by the growing extent to which physicians are expected to make overt predictions about the course and outcome of patients' illnesses and the treatments they undergo, and about their ultimate survival or expected time of death.

Iatrogenic uncertainty has also increased in concatenation with contemporaneous medical advances. As the means of diagnosing and treating disease and illness have become more powerful and efficacious, they have grown more dangerous as well—confronting physicians and their patients with an expanding array of serious, unanticipated side effects that are

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neither easy to prevent nor easy to dispel. The long-standing intellectual and moral tension between attending to the needs and well-being of individual patients and to those of larger collectivities of persons, and the uncertainties that physicians experience about how to reconcile these dual role obligations, have been exacerbated by the resurgence of infectious diseases and the public-health considerations that they entail; by the expansion of managed-care organizations with their aggregate orientation and distributive outlook on the efficient, cost-containing utilization of resources; and by the ascent of what is known as "evidence-based medicine" that, by defining the most reliable and valid empirical data as those derived from large, randomized, controlled clinical trials or from meta-analyses of published studies, tends to shift the focus of clinical practice away from the care of individuals toward the care of populations.

In turn, evidence-based medicine and the debate that currently swirls around its value and its limits are indicative of the epistemological uncertainty that seems to pervade contemporary medicine. Quite paradoxically, the same current medical journals that publish an unending stream of reports on the impressive scientific, technological, and clinical advances and achievements of what historian Roy Porter characterizes as modern "medicine's finest hour"[34] are also replete with articles that raise searching questions about how much of what medical scientists and physicians think they know is real knowledge, who can say when evidence is "good enough" and most likely to be "close to the truth," and about how best to understand and give an adequate account of astute clinical judgment, sound clinical decision making, and the constituent elements of optimal medical care.

Along with attention to medical students' "training for uncertainty," any attempts to improve their social, cultural, psychological, and ethical education should be mindful of the "training for detached concern"[35] process that they undergo as they are carried along by the curriculum toward their formation as physicians. Ideally, physicians are expected to bring "objectivity and empathy, equanimity and [sympathy] into a supple balance with one another—combining and recombining them in

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ways that are compatible with the delivery of competent, sagacious, and humane patient care."[36] As I have emphasized elsewhere, illness and medical work are not only "serious," but also physically, emotionally, and existentially evocative, in ways that are inherently perturbing. Young women and men en route to becoming physicians are initiated into these features of the profession they are entering through a series of rites of passage: medical-school experiences associated with such events as their dissection of a cadaver, their participation in autopsies, their neophyte efforts at taking medical histories from patients and performing their first physical examinations, their contact with disease-inducing pathogens in laboratories and with the spectrum of maladies that beset the patients whom they encounter in their clinical clerkships, the first births that they witness, and the first deaths of patients with whom they have had contact. It is through the impact of such experiences that students undergo their "training for detached concern"—struggling to attain the sort of dynamic equilibrium between composure and compassion that will enable them to function professionally without (to use their word) becoming too "dehumanized." In response to these shared experiences, medical students develop common defense mechanisms that help them to cope with the most psychologically, socially, and ethically difficult and emotive dimensions of their preparation for assuming the physician's role and responsibilities for the care of the patients—defenses that not infrequently are tipped in the direction of self-protective detachment.

Finding ways to transmit more successfully relevant social science and ethical knowledge, reasoning, and insights to medical students not only requires informed awareness of the training for uncertainty and for detached concern that they are undergoing, but also thoughtful inclusion of these aspects of their professional socialization into what is implicitly and explicitly taught.

WHITHER AMERICAN MEDICAL EDUCATION?

It may prove even harder to achieve excellence in this sphere of medical education than it has in the past because of the prob-

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lems that American medical schools and academic health centers are presently facing and the manner in which they are responding to them. In his book *Time to Heal: American Medical Education from the Turn of the Century to the Era of Managed Care,* Kenneth Ludmerer describes, analyzes, and deplores what he characterizes as the progressive "erosion of the intellectual atmosphere" of medical schools throughout the 1990s, and the waning relevance of medical education as a "mission and raison d'être" of academic health centers.[37]

A series of interlocking factors, both internal and external to medical academia, have precipitated this decline. Foremost among them are the wave of concern about escalating health costs and the associated development of a competitive marketplace for medical care that emerged in the 1980s, bringing in their wake an "era of cost containment," and the eruptive growth of predominantly for-profit managed-care organizations on the American medical scene.[38] Academic health centers, with their teaching hospitals and medical schools, have been severely threatened by these and other new forces that have catapulted them into an ongoing struggle to remain financially solvent in a health-care market that has diverted patients and clinical revenues away from them. The financial pressures of managed care have been augmented by the phased-in reductions on Medicare spending through the year 2001, mandated by the 1997 Balanced Budget Act, which sharply decreases the substantial direct and indirect subsidies for medical-school teaching, for residency training, and for indigent as well as paying patients that academic health centers have received from this source for more than thirty years.

One of the ways in which academic health centers have responded to this situation is to greatly increase the number of full-time clinical faculty whose principal, often exclusive responsibility is to see patients rather than to teach or do research.[39] It could be said that many of these clinician-nonteachers are faculty in name only. More and more clinical faculty-members' time is spent in medical practice, which has become the chief source of their salaries and of the income of the academic health centers and medical schools with which they are affiliated. In this business- and money-oriented atmosphere—

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enhanced by the growing number of managed-care contracts under which academic health centers now operate in order to acquire and maintain a sufficiently large patient base—physicians are under intensifying pressure to see as many patients as fast as possible. The length of inpatient hospital stays has been drastically shortened not only as a consequence of biomedical advances (such as the development of less invasive surgical procedures and new forms of anesthesia) and by the increased prevalence of chronic diseases that can be well cared for on an outpatient basis, but also by the economically driven rules of managed-care organizations that restrict the number of days patients are allowed to be hospitalized and the financial coverage for those days. Attempts to move more of clinical education to ambulatory, extra-university settings has not proven to be easy, because community physicians—like their academic colleagues—"are under increasing pressure to be more productive in patient care and may, therefore, not have the time to . . . take students into their practices."[40] These practice conditions have also begun to curtail the time that community physicians feel they can afford to spend as volunteer faculty teaching medical students and university hospital house staff. Furthermore, patients being cared for in private practice are reluctant to be used for medical educational purposes. And medical schools have only begun to tackle the difficulties of being sufficiently cognizant of what kinds of learning experiences students are having in the array of doctors' offices to which they are being sent for training, and of controlling the quality of the education the students receive there.

As a consequence of these deep changes in the organizational, financial, and practice circumstances under which medical education is taking place, and the social and psychological ambiance surrounding them, medical students are being taught by a small percentage of the members of massively large and continually expanding medical-school faculties. Their teaching and learning are occurring in a context where—because of clinical practice, time, and financial pressures—faculty members generally do not have enough contact with students to become their advisors, role models, or mentors. Further, many faculty are demonstrably demoralized by these conditions, and

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by what they view as their adverse effects on the quality of patient care and research, as well as on teaching.[41] It has also become harder for students to observe the phase-movements of disease and the unfolding of its diagnosis and treatment, or to have meaningfully sustained contact with the declining numbers of hospitalized patients—the majority of whom are either admitted for procedures that, under the new health-care ground rules, are considered to warrant no more than overnight stays, or are gravely ill in intensive-care units. This has pushed both faculty and students away from the bedside as a locus of clinical education and made the conference room, distanced from patients, their primary meeting place. Although ambulatory settings have become both more logical and more significant as milieux for medical education, they, too, are beset with what Kenneth Ludmerer has characterized as the high-volume-and-speed "throughput" of patients that subverts the scientific, intellectual, and humanistic excellence of medical education.

It is still unclear what the consequences of educating future physicians under these circumstances will prove to be. But emerging data suggest, for example, that today's medical students and residents may be less skilled in conducting physical examinations, in making clinical observations, and in distinguishing between normal and abnormal physical signs than their predecessors.[42] There is also evidence that negative attitudes toward managed care prevail among them, allegedly influenced by the implicit and explicit "messages" about managed care that they receive from medical-school faculty.[43]

It could be said that the most serious and important social and ethical problems facing American medical education are those that originate in the transformations that medical schools and academic health centers have weathered throughout the last two decades. If this is the case, then any effective plan to better integrate social science and ethics into the teaching of medical students will have to not only take these problems into account, but make them a part of its curriculum. In the present context, however, the long-standing tendency of medical educators to attach "magic-bullet" significance to the power of designated courses to positively influence and professionally shape the attitudes and behavior of medical students and young

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physicians seems unduly optimistic, and somewhat misdirected. As Bernard Lown, emeritus professor of cardiology at Harvard School of Public Health, has provocatively put it, "[T]alking of medical curricula and teaching about human interactive skills" is akin to "living in a Never Never Land. . . . What is the value of interactive skills," he asks, "if you can only spend eight minutes with a patient?"[44]

In conclusion, I do not consider it a denial of the intellectual and attitudinal importance of teaching to state that unless medical academia recognizes the social and moral as well as the economic nature of the intricately entwined educational and health-care delivery issues it is facing, and tackles them *systemically*, one more set of attempted "*nonbiomedical*" curriculum reforms—this time emphasizing courses that interrelate bioethics, medicine, and social science—will fail to make a deep and enduring difference.

ACKNOWLEDGMENT

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ENDNOTES

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[9]I was a member of the Columbia University Bureau of Applied Social Research team that conducted studies in the sociology of medical education throughout the 1950s at Cornell University Medical College, the University of Pennsylvania School of Medicine, the School of Medicine at Western Reserve University, and the University of Colorado School of Medicine. My major research for this project was located at Cornell University Medical College where I spent four years as a participant observer in direct fieldwork contact with the medical school socialization process.

[10]The perspective on American bioethics that I present here, and numerous of the ideas accompanying it, have been progressively developed in some of my previously published papers. See, for example, Renée C. Fox and Judith P. Swazey, "Medical Morality Is Not Bioethics—Medical Ethics in China and the United States," *Perspectives in Biology and Medicine* 27 (4) (Spring 1984): 45–70; Renée C. Fox, "The Sociology of Bioethics," in *The Sociology of Medicine: A Participant Observer's View* (Englewood Cliffs, N.J.: Prentice Hall, 1989), 224–276; Renée C. Fox, "The Evolution of American Bioethics: A Social Perspective," in *Social Science Perspectives on Medical Ethics,* ed. George Weisz (Dordrecht, Boston, London: Kluwer Academic Publishers, 1990), 201–217; and Renée C. Fox, "The Entry of U.S. Bioethics into the 1990s: A Social Analysis," in *A Matter of Principles? Ferment in U.S. Bioethics,* ed. Edwin R. DuBose, Ron Hamel, and Laurence J. O'Connell (Valley Forge, Pa.: Trinity Press, 1994), 21–71.

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[31]Kenneth M. Ludmerer, *Time to Heal: American Medical Education from the Turn of the Century to the Era of Managed Care* (New York: Oxford University Press, 1999).

[32]Renée C. Fox, "Training for Uncertainty," in *The Student-Physician: Introductory Studies in the Sociology of Medical Education*, ed. Robert K. Merton, George Reader, and Patricia L. Kendall (Cambridge, Mass.: Harvard University Press, 1957), 207–241.

[33]The discussion of current patterns of medical uncertainty that follows is abstracted from Renée C. Fox, "Medical Uncertainty Revisited," in *Handbook of Social Studies in Health and Medicine* ed. Gary L. Albrecht, Ray Fitzpatrick, and Susan C. Scrimshaw (London: Sage Publications, forthcoming). The discussion of prognostic uncertainty is based on Nicholas Christakis's book, *Death Foretold: Prophecy and Prognosis in Medical Care* (Chicago: University of Chicago Press, forthcoming).

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[34]Roy Porter, *The Greatest Benefit to Mankind: A Medical History of Humanity* (New York: W. W. Norton & Company, 1998), 718.

[35]Harold I. Lief and Renée C. Fox, "Training for 'Detached Concern' in Medical Students," in *The Psychological Basis of Medical Practice*, ed. Harold I. Lief, Victor F. Lief, and Nina R. Lief (New York: Harper and Row, 1963), 12–35.

[36]Fox, *The Sociology of Medicine: A Participant Observer's View*, 85.

[37]My discussion of the problems that American medical schools and academic health centers are presently facing, and the effects they are having on medical education, is deeply indebted to Kenneth M. Ludmerer's book, *Time to Heal: American Medical Education from the Turn of the Century to the Era of Managed Care*, and also to the three-year project (1992–1995) on undergraduate medical education that Judith P. Swazey and I organized and co-directed under the auspices of the Acadia Institute and the Medical College of Pennsylvania. See the report issued by the project, *Fulfilling the Mission: Medical Schools and the Education of Medical Students* (Philadelphia, Pa.: Medical College of Pennsylvania and Hahnemann University, 1996).

[38]Ludmerer, *Time to Heal.*

[39]During the ten-year period covering the academic years 1984–1985 through 1993–1994, there was an overall increase of 53.6 percent in the full-time medical school faculty. The number of medical students decreased by slightly less than 1 percent during that same period (*Fulfilling the Mission*, 12). In the 1996–1997 academic year, a further 4.5 percent increase in the full-time medical school faculty members occurred. The first-year enrollment of medical students for the class entering in 1996 was 16,905, the lowest since 1990. Barbara Barzansky, Henry S. Jonas, and Sylvia I. Etzel, "Educational Programs in U.S. Medical Schools, 1996–1997," *Journal of the American Medical Association* 278 (9) (September 1997): 744, 746. In the 1997–1998 academic year, the number of full-time medical faculty increased once again, but this time only 1.2 percent over the previous year, from 95,568 to 96,773. Most of the increase took place in clinical departments; the number of full-time faculty members in the basic science departments remained virtually unchanged. The number of enrolled medical students—66,748—also remained relatively constant. Barbara Barzansky, Henry S. Jonas, and Sylvia I. Etzel, "Educational Programs in U.S. Medical Schools, 1997–1998," *Journal of the American Medical Association* 280 (9) (2 September 1998): 803, 805.

[40]Barzansky, Jonas, and Etzel, "Educational Programs in U.S. Medical Schools, 1997–1998," 803.

[41]Steven R. Simon et al., "Views of Managed Care: A Survey of Students, Residents, Faculty, and Deans at Medical Schools in the United States," *New England Journal of Medicine* 340 (25 March 1999): 930.

[42]Abigail Zuger, "Are Doctors Losing Touch with Hands-On Medicine?" *New York Times*, 13 July 1999, F1, F9.

[43]Simon et al., "Views of Managed Care," 932–934.

[44]Quoted in Cari Coleman, "Medical Schools Training for Reality of Managed Care," *Association of American Medical Colleges Reporter* 8 (9) (June 1999): 11.

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Ultimately, we will have to engage the more ominous aspects of globalization, such as the commercialization of suffering, the commodification of experiences of atrocity and abuse, and the pornographic uses of degradation. Violence in the media, and its relation to violence in the streets and in homes, is already a subject that has attracted serious attention from communities and from scholars. Regarding the even more fundamental cultural question of how social experience is being transformed in untoward ways, the first issue would seem to be to develop historical, ethnographic, and narrative studies that provide a more powerful understanding of the cultural processes through which the global regime of disordered capitalism alters the connections between collective experience and subjectivity, so that moral sensibility, for example, diminishes or becomes something frighteningly different: promiscuous, gratuitous, unhinged from responsibility and action. There is a terrible legacy here that needs to be contemplated. The transformation of epochs is as much about changes in social experience as shifts in social structures and cultural representations; indeed, the three sites of social transformation are inseparable. Out of their triangulation, subjectivity too transmutes. The current transformation is no different; yet perhaps we see more clearly the hazards of the historical turn that we are now undertaking. Perhaps all along we have been wrong to consider existential conditions as an ultimate constraint limiting the moral dangers of civilizational change.

Arthur Kleinman and Joan Kleinman

From "The Appeal of Experience; The Dismay of Images: Cultural Appropriations of Suffering in Our Times"
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Charles E. Rosenberg

Meanings, Policies, and Medicine: On the Bioethical Enterprise and History

ONE CAN HARDLY IGNORE the widely shared conviction that we are living through a period of crisis in health care. And that crisis is more than economic and administrative, though its most egregious symptoms present themselves in these interrelated forms. One need only pick up a newspaper or magazine to be reminded of the omnipresent and multidimensional nature of the problems confronting American medicine. Many of those perceived dilemmas turn on rapid technical change and the difficulty of creating an institutional and economic, as well as moral, context in which these new clinical, policy, and research options can be managed. Not surprisingly, bioethics is often invoked—as both symptom and possible remedy—in discussions of these jarring realities. How are we to think about this enterprise, site it in social space, and understand its several interrelated identities? These are not easy tasks. Contemporary bioethics constitutes a particularly elusive challenge for the historian; value assumptions have always shaped medicine as a social enterprise, yet those values have been often implicit and unspoken, the moral common sense of each generation interacting with technical, professional, institutional, and economic factors to configure a time-specific set of clinical realities.

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MEDICAL CARE AND SOCIAL OBLIGATION

For this historian of American medicine, some of the markers of contemporary change are particularly striking. The *New York Times,* for example, reported in 1998 that Montefiore Hospital had announced its intention of entering into a joint venture with a for-profit corporation; it planned to open a chain of 24-hour cancer and HIV clinics. "The No. 1 problem for not-for-profit institutions," the president of Montefiore explained, "is capital formation."[1] In my own city, Philadelphia, the Pennsylvania Hospital, America's oldest general hospital, first sold its historically important psychiatric division to a for-profit provider, then sold itself, after an independent existence of a quarter of a millenium, to a rather more youthful entity called the University of Pennsylvania Health System, which announced its plans to send four "experts in 'clinical reengineering' to look for ways to make cost-effective changes in clinical care" at its new acquisition.[2] The Hospital of the University of Pennsylvania had just finished its own "reengineering." Even more recently, the Philadelphia region's health-care system has been destabilized and demoralized by the aggressive takeover strategy of a Pittsburgh-based health-care system, which purchased physician practices, hospitals, and associated medical schools in a bold marketplace venture that soon ended in bankruptcy, unmet commitments, and a perilous future for such historically significant institutions as Hahnemann Medical College and the Medical College of Pennsylvania.[3]

Particularly revealing among my collection of recent media indicators is an ironic—and enlightening—juxtaposition of stories on the front page of the *New York Times.*[4] In the upper right-hand corner was a report that National Institutes of Health (NIH) funding was likely to be increased in next year's budget. And, it was explained, cancer could be understood and treated. "We are in a golden age of discovery," the director of the National Cancer Institute (NCI) contended, "one unique in human history. . . . Knowledge about the fundamental nature of cancer is exploding." Basic science was closing in on mankind's ancient enemy, and relentless Washington lobbying could be relied on to nurture this laudable enterprise. A coalition of

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interested parties—patient advocacy groups, doctors, and medical schools—had joined in supporting an effort to double the NIH budget over the next five years. "We plan a grass-roots campaign inside and outside the Beltway," the president of their lobbying firm explained candidly: "It will be run the same way Northrop Grumman lobbies for the B-2 bomber." Immediately to the left of this upbeat and uninflected report of promised laboratory achievement was a background story on the emotional and physical pain associated with the multiple births resulting from contemporary fertility treatments: "Joy and Sorrow follow Medical Miracle" read one of the subtitles in this sobering overview.[5] Whether the placement of these stories on the front page of the *Times* was a compositor's whim or an implicit editorial comment, the message seems undeniable. Technology, market incentives, and public policy have changed and are changing every aspect of medical care, while society has been less than successful in anticipating the consequences of such change.

The Fall 1998 special issue of *Life*, to cite a related example, was devoted to "Medical Miracles for the Next Millennium." The cover promised "21 Breakthroughs That Could Change Your Life in the 21st Century: Gene Therapy/Edible Vaccines/Memory Drugs/Grow-Your-Own Organs." Little attention was paid in the magazine's worshipful depiction of laboratory progress to the ironic and seemingly paradoxical growth of a widespread fear of that technology's human implications. Similarly illuminating was an issue of *Time* on "The Future of Medicine." The subtitle promised to explain "how genetic engineering will change us in the next century." The striking cover illustration was a stylized caduceus, a snake's head morphing into a coil of DNA.[6] How better to symbolize medicine's changing and conflicted shape in a world of relentless laboratory progress and media-heightened public expectations? The cover's powerful visual metaphor represents as well two seemingly inconsistent yet mutually constitutive aspects of contemporary medicine: the technical and the sacred—the cultural power of laboratory novelty and the persistence of a self-conscious ethical tradition.

I would argue that this brief sampling of media reports provides a useful microcosm of a structural and emotional macro-

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cosm. It illustrates not only a perceived crisis in public policy, but a fundamental inconsistency between values and expectations, as well as the concrete social and economic relationships in which such convictions and perceptions are necessarily embedded.

Our health-care system is marked by a characteristic disconnect: on the one hand, boundless faith in the power of the laboratory and the market, on the other a failure to anticipate and respond to the human implications of technical and institutional innovation. And this dilemma grows directly out of our expansive faith in technical solutions to clinical problems; as we are well aware, sickness, pain, disability, and death are not always amenable to clinical intervention. In the late twentieth century, such conflicts are both public-policy issues and, inevitably, elements in individual doctor-patient relationships. The question, of course, is relating the particular to the general, understanding the choices that face individuals in recurring social interactions—in some sense weighing and understanding degrees of individual autonomy, of professional and collective social obligation. I would contend that bioethics must ultimately address such questions and issues that are necessarily historical and unavoidably moral: the move from the individual to the social, from meaning to structure in terms of medicine, from the clinical encounter to the larger society in which that encounter takes place.

MEDICINE AND MEANINGS

To a historian, many of the dilemmas that beset contemporary medicine are strikingly different from parallel realities in previous American generations. The world of social value, and thus obligation, was very different, for example, when the Montefiore Home for Chronic Invalids opened its doors in 1884, and certainly when the Pennsylvania Hospital was established in the 1750s. Pious and paternalistic activism, the exchange of care for deference, were as central to the eighteenth- and early nineteenth-century hospital as monetary exchange was alien to it. Class and dependence as much as diagnosis determined one's place in a "system" of health care sited largely

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in the home, and in which institutional care was limited essentially to the urban poor.[7] In fact, the late-twentieth-century term "health-care system," with its assumption of a complex, multilayered, bureaucratic, interactive, and, by implication, public world of medicine, is irrelevant to an era without specialists and laboratories, an era in which the great majority of medical care was performed in the patient's home, whether by family members or professional physicians. The worthy poor were presumed to deserve voluntary hospital care without incurring the stigma that came with almshouse admission. Physicians were presumed to have an obligation to provide gratuitous or discounted care to those unable to afford their fees. Whether rural or urban, nineteenth-century Americans were presumed to have a right to such care, but not, of course, to equal—class-blind—care.

The public sector played a role in the provision of health care, but only in regard to the dependent, not to those seen as able to care for themselves. A socially constructed sense of stewardship, of categorical moral obligation, motivated and shaped the efforts of our earliest hospitals' founders. They did not expect to be judged primarily by the success or failure of marketplace decisions (though they were expected to function responsibly within the market). The medical profession was presumed, at least in theory, to be motivated by a code of gentlemanly and selfless benevolence; patenting discoveries—like advertising one's clinical services—was, for example, seen as evidence of sordid quackery, not rational market behavior. Economic competition was understood to be not a guarantor of economically efficient health care but an ever-present motivation for misrepresentation and shoddy practice.

In 1800, medical ideas and medical practice were widely distributed throughout society—in patterns vastly different from those to which we have become accustomed in the late twentieth century. Conventional moral values suffused both lay and professional ideas of disease causation and treatment, for example, but were not legitimated in terms of modern notions of specific, mechanism-defined disease. Disease categories did not, logically enough, play so prominent a role in lay understandings of behavioral deviance, or in physicians' understanding of

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appropriate therapeutic and diagnostic choices. Homosexual behavior was a willed act of immorality, for example, not a disease, personality type, or merely one among a variety of lifestyle patterns; disruptive grammar-school children were wicked and undisciplined, not victims of Attention Deficit Hyperactivity Disorder. Death involved prognosis and pain, confrontation with a patient's spiritual and aggregate physiological status, not the management of machines and the hegemony of bureaucratic protocols and insurance schemes. Euthanasia meant literally that—an easy death—and implied the deployment of opiates, moral reflection, and family, not respirators and advanced directives.[8] Research had not yet come to embody a transcendence rivaling that of traditional religion and community obligation.

There are, of course, continuities as well as contrasts between the late eighteenth and the late twentieth centuries. Chronic disease, for example, posed questions of behavior, volition, and regimen—just as today's anxieties about risk factors and lifestyle mobilize feelings of guilt and accountability.[9] And men and women felt pain, feared death, mourned the loss of loved ones—as they still do.

My argument will have become clear enough by now. I have tried to illustrate in concrete terms the way in which morality and moralism, obligation and responsibility are unavoidable elements of medical care, and at the same time contingent and historical. Medical ideas and practices have always reflected, incorporated, and sanctioned prevailing notions of value and responsibility. Such ethical assumptions imply priorities and constrain choice; meaning and morality are thus necessarily and inextricably embedded in every aspect of medical practice: private and public, individual and collective.

NOVEL REALITIES

If anything can be said to characterize our particular moment in the relationships among the linked histories of medicine, culture, and public policy, it is, as I have emphasized, a novel sense of change and conflict, an uncomfortable awareness of the difficulties inherent in balancing the sacred and the techni-

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cal, the individual and the collective, in configuring the rights of physicians, individual patients, and the general good. It was, in fact, out of such perceived conflict that bioethics itself developed as a self-conscious movement in the 1960s and early 1970s. Its very creation was in part a symptom—as well as a recognition—of perceived inequity, of a gap between medicine's presumably sacred and humane tradition and a reality often egregiously inconsistent. It was an acknowledgment that something needed to be done.[10]

In another sense, this gap between medicine's humane tradition and a more complex and compromising reality can be thought of as a structured crisis in supply and demand: a demand constituted by pain and anxiety and the inexorable realities of demography and chronic disease, yet routinely construed in terms of procedures and specialists.[11] Americans have produced a reservoir of insatiable clinical demand ill-suited to a world of supply dominated by technology, by impersonal—and costly—providers and products.

This asymmetry embodies a structured conflict that a minority of far-sighted social scientists and physicians have warned about since the progressive era at the beginning of the present century, when such critics deplored a growing medical impersonality and dependence on what they already saw as increasingly pervasive technology. Such anxieties might, in fact, be seen as precursors of the late-twentieth-century bioethics movement—an affirmation of the individual and the idiosyncratic as opposed to the depersonalization and fragmentation of care implied by clinical pathology, specialism, and reductionist understandings of health and disease. We have experienced a century of recurrent crisis in how we think about medicine and what we expect from it. We seem to have created a system in which material expectations are bound to disappoint, and in which we increasingly and paradoxically keep trying to reach personal (that is, intangible, experiential, and holistic) ends, through technical and mechanism-oriented—reductionist—means.

Another recent bit of media evidence illustrates this point more concretely. *Newsweek* recently featured an article on the genetic causation not only of clinically well-defined mental

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illness but also of a bewildering variety of human peculiarities, all construed as less severe manifestations (shadow ailments caused by the presence of one or more "abnormal" genes) of a multi-genic illness.[12] "Idiosyncratic behaviors and personality quirks once thought merely 'odd' or 'interesting' might be, in a sense, mental illnesses," the *Newsweek* reporter explained, "a reflection of an abnormality in the brain, and even in the genes."

Though perhaps at first thought unrelated to the previously mentioned changes in such historically significant institutions as Montefiore and the Pennsylvania Hospital, or to understanding the social place of bioethics, this newsmagazine story illustrates a fundamental and in fact logically related aspect of twentieth-century medicine: its characteristic search for mechanism-based understandings of an ever wider range of human behaviors. This relentless medicalization of both normal and deviant behavior sheds a parallel and supplementary light on a fundamental structural reality in our health-care system: the tendency to ask medicine to do more and more cultural work, while demanding that this cultural work be legitimated in terms of biological mechanism. It is in part a crisis—as illustrated in the *Newsweek* story on the genetic determination of practically everything—of how we legitimate norms, manage deviance, think about ourselves. Behavior, agency, culture itself can be ingenuously reduced to neurochemical mechanisms, even if this determinism continues to dismay those anxious to maintain a place for human agency and individual responsibility.

This structure of linked ideas and institutional relationships poses a number of problems for both historian and bioethicist. Perhaps most fundamental is the way in which ideas, values, and expectations become embedded in institutions, in practices, and in economic relationships and interests. Second is the way in which the concepts and practices of medicine have become increasingly central to the everyday lives of men and women, metastasizing on to the business and editorial as well as the news pages; we seem well on the way to medicalizing not just deviance, but almost every aspect of daily life. Third is the way in which medicine is simultaneously within and outside the market, a paradox that frames today's most vexing organiza-

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tional question: Can the market (as mediated through public advocacy and the political process) prove adequate as a means of distributing clinical equities and outputs, when demand is defined in more than material terms? Can the market produce rational and rationalized (collective) solutions that must be experienced in moral and emotional (individual) terms?

The bottom line, as I have tried to emphasize, is that we cannot remove or isolate value assumptions from the institutional, the technical, and the conceptual in medicine; men and women inevitably express their sense of need and priority in the public sphere. Medicine is negotiated and inevitably political, and, as we have come to understand more generally, the political is cultural. The heated contemporary debate surrounding managed care illustrates in a very concrete way the nature of such interconnections between values and interests. Questions that can be framed as matters of justice and autonomy are at once questions of control and economic gain. Perceptions of right and wrong, of appropriate standards of practice, constitute *de facto* political realities—variables in negotiating choices among rival policies as well as in particular clinical interactions. The widespread assumption, for example, that it is right for government to play a role in providing and regulating health care is a specific historical and ethical, and thus political, reality. And so is the equally pervasive assumption that it is somehow immoral for mere economic calculation to constrain a physician's clinical decision making. Our willingness, in fact, to nurture bioethics similarly constitutes a public recognition of medicine's special moral identity.

But this vague moral consensus cannot mandate a precise and unambiguous social agenda for bioethics. The new enterprise has been charged with a difficult and elusive job. We live in a fragmented yet interconnected world, a world of ideological and social diversity, of inconsistency and inequity, of change and inertia. We cannot discuss relationships among men and women who differ in power and knowledge without acknowledging those inequities: class, geography, gender, race, and education all modify the category *patient*; economic incentives as well as the institutional and intellectual structures of medicine (such as specialty and organizational affiliation) modify

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the category *physician*. A growing awareness of such complexities has made bioethics an increasingly labile and self-conscious enterprise. And perhaps a less self-confident one as well: articulating and applying a foundational ethical basis for particular social actions no longer seems an easily attainable goal.

Inconsistent ideas as well as social diversity shape available choices for both physician and patient. Our society has elaborated and internalized not a unified and coherent moral consensus, but rather a world of medical discourse and practice marked by the claims of three competing and not always consistent transcendences. One is the academic research tradition with its worship of the selfless search for knowledge and a widespread faith in its inevitable application. It is a kind of secular millennialism, powerful not simply because it is a source of undifferentiated cultural optimism, but because it is structured into the expectations and hopes of individuals: into the career choices of particular physicians and scientists, into the formation of public policy, and into the status and programs of academic departments and teaching hospitals.[13] Second, and more recent, is the worship of system as goal and ideal, the assumption that the optimum general good is attainable only through an optimum configuration of market and institutional relationships. Finally, of course, is the traditional moral specialness of medicine, respect for physician responsibility and the rights of individual patients—a tradition that can be traced from classical antiquity to contemporary debates over medical care. Each of these claims to transcendence legitimates claims to social authority; all are ceaselessly configured and reconfigured as medicine's technical resources and institutional forms evolve and pose novel research and clinical options. Bioethics has in fact already become a substantive actor in the complex interactions that characterize relations among these realms of value and implicit power.

I have tried in the preceding pages to illustrate a number of the ways in which the moral values that suffuse medicine are historically constructed and situationally negotiated, like every other aspect of culture, and not simply derived from the formal modes of analysis that have historically characterized theology

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and moral philosophy (though such delineations of fundamental principle are in themselves an element in the social negotiations that inform and rationalize health care). The formulations of credentialed philosophers and theologians are at once a claim to cultural authority and a factor in the public mediation of social conflict.

BIOETHICS AS HISTORICAL SUBJECT

The very existence of a socially visible enterprise called bioethics is a recognition of the recurrent structured conflicts I have tried to illustrate anecdotally. Thus, I began this discussion with particular examples of institutional change because I wanted to emphasize the ways in which the history of bioethics underlines medicine's context dependence, and, in particular, the way in which medicine necessarily embodies a variety of attitudinal and value elements as well as technical capacity and institutional practice.

But this is only one of the ways in which bioethics and history relate. First, from the historian's disciplinary perspective, bioethics is a complex and potentially revealing subject for empirical investigation. Second, and more important, I would contend that although academic history and bioethics have in general followed separate paths, they share a potential community of sensibility, a sensitivity to context and to the relationships among individual perception, social constraint, and the situatedness of human agency. Practitioners of history and bioethics should, finally, be similarly aware of the importance of irony and contingency, of the gap between theory and practice, conscious intent and unforeseeable outcome.

The still-brief history of American bioethics demonstrates just such realities. As a social movement, bioethics developed in the mid-twentieth century as a critical enterprise, a response to felt inhumanities in our system of health care and biomedical research. A response to specific abuses, bioethics has remained practice-oriented; society expects bioethics to solve or at least ameliorate insistently visible problems.

Growing as it has out of a sense of moral outrage, bioethics has had an undeniable impact on everyday clinical realities. Yet

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from the historian's perspective, this novel enterprise has played a complex and in some ways ambiguous role. Bioethics not only questioned authority; it has in the past quarter-century helped constitute and legitimate it. As a condition of its acceptance, bioethics has taken up residence in the belly of the medical whale; although thinking of itself as still autonomous, the bioethical enterprise has developed a complex and symbiotic relationship with this host organism. Bioethics is no longer (if it ever was) a free-floating, oppositional, and socially critical reform movement: it is embodied in chairs and centers, in an abundant technical literature, in institutional review boards and consent forms, in presidential commissions and research protocols. It can, that is, be seen as a mediating element in a complex and highly bureaucratic system that must, nevertheless, manage ceaseless technical change. It is not an accident that the bioethical enterprise has routinely linked bureaucracy—committees, institutional regulations, and finely tuned language—with claims to moral stature.

But this functional role implies a structured conflict. By invoking and representing medicine's humane and benevolent, even sacred, cultural identity, bioethics serves ironically to moderate, and thus manage and perpetuate, a system often in conflict with that idealized identity. In this sense, principled criticism of the health-care system serves the purpose of system maintenance. It is such paradoxes of power and consciousness that explain why bioethics needs to think of itself both historically and politically. And in some ways this process has already begun.[14] Bioethics has already enshrined its heroes and villains—Henry Beecher and Josef Mengele—and commemorated its sacred places—Willowbrook, Tuskegee, Nuremberg. In fact, one could argue that the historical stock-taking initiated by bioethics' founding generation is itself an aspect of what might be called institutional consolidation.[15]

Participant histories serve celebratory and mystifying as well as analytical and self-critical ends. History can be used to demonstrate both false consciousness and a celebration of conscience. It is difficult for the committed practitioner not to emphasize her field's positive values and accomplishments, not to see herself on the side of the angels, fighting the good fight

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against the routine and unself-conscious abuse of men and women in everyday clinical and research settings. It is equally difficult to see the apparatus of committees and regulations that protect patient rights against the abuses of an impersonal technology as itself a technology. By way of example, let me quote the words of a bioethicist reacting to an earlier version of my present remarks, and in particular to a passage in which I described the bioethical enterprise as in some ways a technology necessarily mirroring the technology it sought to ameliorate. "Bioethics," the indignant reader explained, "in the late twentieth century in American medicine has always championed the rights of the individual patient against the vagaries of the medical system. Its cardinal principles of autonomy, beneficence, non-maleficence, and justice represent the antithesis of technology."[16]

Most contemporaries would not be quite so uncritical in their self-evaluation, yet are still ill-prepared to deal with what I have characterized as the central irony of bioethical success: insofar as it has been accepted by the world of research and clinical practice, it has become a part of those linked enterprises, and thus its every criticism and consequent procedural reform cannot help but constitute an aspect of biomedicine's public moral face.

As a specific empirical subject, moreover, bioethics presents an elusive aspect—as elusive as weighing its ultimate social impact. In part this is because the bioethical enterprise is an aggregate of three not-always-consistent activities. One is the elaboration of formal doctrine, the job of individuals trained to articulate and address normative ethical questions. I refer, of course, to those philosophers and theologians who have sought to create a principled consensus around such policy-defining issues as autonomy, beneficence, and justice. Second is the role of bioethics in mediating day-to-day clinical problems in particular social settings. I have in mind the innumerable contexts in which institutional review boards, government commissions, and the language and ritual of informed consent make practitioners and researchers aware of the rights of patients and subjects. Third is the way in which the bioethical enterprise figures in public discourse, responding in newspapers, periodi-

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cals, television, and—in recent years—the Internet to novel dilemmas derived often, but not always, from technological innovation. In this public capacity bioethics reassures, implying that there is a discernible moral order that can be used rationally to manage new and potentially alarming clinical and research choices. It is both ritual and spectacle, acting out the several reassurances of ethical concern, credentialed expertise, and the assumption that fundamental ethical principles can be discerned and applied.

Thus bioethics occupies three distinct (if often overlapping) social spaces. One is academic, formal, discipline- and text-oriented. A second is the hospital and research settings, where bioethics has an institutionalized presence. Third, as I have suggested, is the media. This mosaic of roles and sites of social action makes bioethics both complex in structure and difficult to delineate. This diversity of site, personnel, and function also explains my avoidance of the term "discipline" in describing what I have chosen to call instead the bioethical enterprise: a conglomerate of experts, practices, and ritualized and critical discourse in both academic and public space.

BIOETHICS AND THE HISTORICAL SENSIBILITY

I have specified a number of ways in which bioethics and history might share an analytic perspective. First, and perhaps most fundamentally, I would argue, the task of ethical understanding should parallel the historian's job of cultural reconstruction: both kinds of practitioners should seek—if necessarily imperfectly—to understand a time- and place-specific structure of choices as perceived by particular actors. Second, I would argue that we cannot understand the structure of medical choice without an understanding of the specific histories of medicine and society that have created those choices. This was the argument I hoped to illustrate in my earlier recounting of change in contemporary American hospitals and my emphasis on increasingly reductionist understandings of disease. And third, and perhaps most disquieting, we must historicize bioethics itself. For it is clearly a time-bound enterprise, with complex

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relationships to the special world of medicine and to the larger society in which medicine is nurtured and which medicine in part constitutes.

My first point, which seems no more than a truism to a cultural historian, will seem irrelevant or perhaps even philistine to scholars focused on the elucidation of ethical principles abstracted from precise social and institutional contexts—even if motivated by abuses at just such specific sites. Moreover, such formal styles of normative discourse parallel and intensify the historical tradition of medical ethics with its emphasis on the unmediated doctor-patient dyad: one doctor, one patient, one bedside, the paradigmatic vexed case. From the contextually oriented historian's point of view, however, choice is always constrained and structured, a reality to be understood in specific situations, not schematically in terms of logically and morally coherent ends. In this historical and sociological sense, autonomy is a product, not a goal; it is a place-, time-, and system-specific outcome of the interaction between the microcosm of the clinical encounter and the macrocosm(s) of the larger society and the cognitive and institutional world of medicine. This needs hardly be elaborated at a moment in time when many physicians find their clinical interactions limited by managed care providers to fifteen minutes and their diagnostic and therapeutic choices limited as well. Autonomy and agency are constructed and reconstructed in every healing context. There can be no decontextualized understanding of bioethical dilemmas; bioethics is definitionally contextual, as I have argued, finding its origins in the search for particular solutions to visible social problems. A decontextualized approach in bioethics is not simply a matter of disciplinary style; it is a political act.

Discussions of informed consent, for example, that abstract the actors—clinicians, researchers, patients, and "subjects"—from their particular social roles and individual identities are not very helpful and must in fact mystify these social relationships, and, in doing so, legitimate the *de facto* authority of those individuals and institutions doing the "consenting."[17] At the risk of seeming didactic, let me take a moment to underline the way in which the colloquial use of "consent" as a verb illuminates the ambiguity of routinization in the management of

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"autonomy" and "beneficence." This usage is a syntactical representation of power and comparative powerlessness, of actor and the object of that actor's actions. To consent a patient is to act out—and legitimate—a reality of social inequality as well as to demonstrate the existence of a self-conscious community of "consenters" well aware of the ritual and hierarchical aspect of this now pervasive ethical mechanism.

I would argue, moreover, that bioethics is not only defined by its context of use but that it cannot be self-aware without an understanding of the history of medicine in the past century: of the roles played by new and specific notions of disease, by the growth of specialism and credentialing, by the siting of the clinical encounter in a technologically rationalized and structured institution instead of the individual home or physician's office. This point hardly needs elaboration. Bioethics is, or should be, a social and a historical enterprise, for the issues it seeks to mediate are themselves the products of a specific, determining history. Without history, ethnography, and politics, bioethics cannot situate the moral dilemmas it chooses to elucidate. It becomes a self-absorbed technology, mirroring and inevitably legitimating that self-absorbed and all-consuming technology it seeks to order and understand.

But, as I have suggested, it is easier to call programmatically for bioethics to place itself and its tasks historically than to accomplish that task. There is no simple path to understanding the historical place of bioethics but rather a variety of interpretive options, reflecting the interpreter's point of view and the inherent elusiveness of the subject. The enterprise elicits a diversity of perspectives. To some critics on the Left, bioethics is no more than a kind of hegemonic graphite sprayed into the relentless gears of bureaucratic medicine so as to quiet the offending sounds of human pain. Its ethical positions, this argument maintains, are, in terms of social function, no more than a way of allaying social and legal criticism, and are merely the self-reproaches of a minority of ethically-oriented physicians. Bioethics has, moreover, according to this position, focused too narrowly on the visible problematic instance—on the plug pulled or not pulled, on the organism cloned or the cloning interdicted—and avoided consideration of less easily dramatized

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policy debates and mundane bedside dilemmas. And, finally, these critics contend, it is not surprising that in a bureaucratic society we have created a cadre of experts and a body of knowledge to provide a soothing measure of humanity, certified and routinized.

To its sophisticated practitioners and advocates, on the other hand, bioethics is a humane change agent, an important mechanism for mediating technological and institutional change, a kind of software that facilitates the adaptation of novel varieties of hardware. It is, the argument states, a genuine constraint, a substantive actor in a complex renegotiation of everyday medical practice; bioethics has, similarly, influenced the conduct of clinical research with human and animal subjects. One need only point to the creation of research guidelines for human and animal subjects, to the existence of institutional review boards, and to good-faith attempts to make informed consent a reality. Even if an unfettered individual autonomy may be an unrealizable ideal, the assumption nevertheless that there is such a thing contributes to a viable framework for thinking about transcendent value, constitutes in itself a resource in the complex negotiations that determine and constrain individual and institutional choice. Bioethics has also played a constructive role in the public discourse surrounding clinical medicine and biomedical innovation, a media discourse that is necessarily focused on particular problems as spectacle yet in such perception-altering acts changes our structure of political choice.[18] Perhaps most important, bioethics expresses the widely felt social—and thus political—assumption that medicine is and must be more than a sum of technical procedures and market transactions. It promises solutions to human dilemmas beyond the impersonal profit-maximizing choices of the market or the ultimately elusive if seductive dreams of technological utopianism.

HISTORY, CONTINGENCY, AND BIOETHICS

Just as the three principles of value in real estate are location, location, location, for history they are context, context, and context. And irony and contingency are implicit in a contextual style of analysis; history, like life itself, is filled with unintended

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consequences. But in one respect historians are more fortunate than bioethicists: no one expects them to solve emergent social problems. The bioethical enterprise, on the other hand, originated, as we have seen, as a response to such perceived problems and continues to offer not just analysis of but solutions to them.

Yet the most profound of such problems are, in their nature, unsolvable. We are well aware that there is no ultimate solution for pain and death, no way to explain the brutal randomness with which suffering is distributed. These are aspects of the human condition. Some other issues are perhaps less obvious. There is also no easy solution, for example, to the way inequalities of social identity reenact themselves in medical care. Another paradox grows out of our natural yet contradictory desire for cure and care, for technological efficacy with a human face. But care and cure are not easily linked in one context; the historical circumstances that produce the laboratory's undeniable achievements also produce the bureaucracy that intimidates, fragments, and distances. A parallel conflict grows out of the difference between interest as defined by the individual and interest as defined by the collective; a test or procedure that can benefit one individual might be irrational from the social system perspective. Ours is a health-care system, moreover, that has consistently demonstrated the ability to incorporate the critically and morally oppositional and make it an aspect of the system itself. And this, perhaps, is the ultimate irony of bioethics' history: the persistent yet perhaps illusory quality of our desire to routinize the humane, to formulate and safeguard timeless values in a world of ceaseless change, social inequality, and utopian laboratory expectations.

ENDNOTES

[1]Esther B. Fein, "Region to get Clinics giving Specialty Care," *New York Times,* 9 February 1998, B1.

[2]Andrea Gerlin, "A Venerable Phila. Hospital Charts a New Course," *Philadelphia Inquirer,* 1 February 1998, D1; for background on the sale of the Institute of the Pennsylvania Hospital, see Karl Stark, "Talk Isn't Cheap, Forcing Changes in Psychiatry," *Philadelphia Inquirer,* 14 September 1997, E1.

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[3]Hahnemann was founded as America's premier homeopathic training institution in 1848, and the Medical College of Pennsylvania is better known to historians by its original appellation: the Woman's Medical College, a pioneer institution founded in 1850. In 1993, the two schools announced their intention to merge under the auspices of the Pittsburgh-based Allegheny Health, Education, and Research Foundation; they admitted their first class two years later. Cf. Naomi Rogers, *An Alternative Path: The Making and Remaking of Hahnemann Medical College and Hospital of Philadelphia* (New Brunswick and London: Rutgers University Press, 1998); Gulielma F. Alsop, *History of the Woman's Medical College: Philadelphia, Pennsylvania, 1850–1950* (Philadelphia: J. B. Lippincott, 1950).

[4]Robert Pear, "Medical Research to Get More Money from Government: An Investment in Health," *New York Times,* 3 January 1998, A1.

[5]Pam Belluck, "Heartache Frequently Visits Parents with Multiple Births," *New York Times,* 3 January 1998.

[6]*Time,* 11 January 1999.

[7]Which is not to say that such variables are not significant. See, for example, Charles E. Rosenberg, *The Care of Strangers: The Rise of America's Hospital System* (New York: Basic Books, 1987); Morris J. Vogel, *The Invention of the Modern Hospital: Boston, 1870–1930* (Chicago and London: The University of Chicago Press, 1980); Dorothy Levenson, *Montefiore: The Hospital as Social Instrument, 1884–1984* (New York: Farrar, Straus & Giroux, 1984).

[8]See, for example, William Munk, *Euthanasia: Or, Medical Treatment in Aid of an Easy Death* (London: Longmans, Green, and Co., 1887).

[9]Cf. Allan M. Brandt and Paul Rozin, eds., *Morality and Health* (New York and London: Routledge, 1997).

[10]Although it is conventional to see the bioethics movement as having its late-twentieth-century origins in Nuremberg, it is equally conventional to see it crystallizing as a self-conscious movement in the 1960s as, in part, a response to those social currents that produced a more general sensitivity to individual rights—of women, prisoners, and sexual and racial minorities—and as an anti-authoritarian skepticism toward credentialed expertise. See, for a first generation of bioethics history, Albert R. Jonsen, *The Birth of Bioethics* (New York and Oxford: Oxford University Press, 1998); David J. Rothman, *Strangers at the Bedside: A History of How Law and Bioethics Transformed Medical Decision Making* (New York: Basic Books, 1991); George J. Annas and Michael A. Grodin, eds., *The Nazi Doctors and the Nuremberg Code: Human Rights in Human Experimentation* (New York and Oxford: Oxford University Press, 1992).

[11]I do not mean to imply that medical practice has in fact been invariably humane, caring, and selfless over time, but rather that a commitment to this ideal has always been part of the profession's formal corporate identity.

[12]Sharon Begley, "Is Everybody Crazy?" *Newsweek,* 26 January 1998, 51–55.

[13]For an argument emphasizing the nineteenth-century roots of such discipline-structured patterns of value and action, see Charles E. Rosenberg, *No Other*

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Gods: On Science and American Social Thought, 2d ed., rev. (Baltimore and London: The Johns Hopkins University Press, 1997).

[14]Cf. Jonsen, *The Birth of Bioethics*; Rothman, *Strangers at the Bedside*; George Weisz, ed., *Social Science Perspectives on Medical Ethics* (Philadelphia: University of Pennsylvania Press, 1990); Albert R. Jonsen, ed., "The Birth of Bioethics," Special Supplement, *Hastings Center Report* 23 (1993); Ruth R. Faden and Tom L. Beauchamp, in collaboration with Nancy M. King, *A History and Theory of Informed Consent* (New York and Oxford: Oxford University Press, 1986).

[15]For a deeply informed guide to this history by an influential participant, see Jonsen, *The Birth of Bioethics.*

[16]Personal communication, Sheldon Lisker, M.D., to the author, 1 February 1999.

[17]For an illuminating case study, see Renee R. Anspach, *Deciding Who Lives: Fateful Choices in the Intensive-Care Nursery* (Berkeley, Los Angeles, and London: University of California Press, 1993).

[18]The recent media achievement of Dr. Jack Kevorkian in making end-of-life issues a public topic is a case in point.

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Charles L. Bosk

Professional Ethicist Available: Logical, Secular, Friendly

Problem resolution through ethics based decisionmaking. Professional ethicist provides practical supportive help with personal decisions. Logical, Secular, Friendly

—personals' advertisement[1]

WRITING IN 1919, Max Weber said:

> Consider modern medicine, a practical technology which is highly developed scientifically. The general "presupposition" of the medical enterprise is stated trivially in the assertion that medical science has the task of maintaining life as such and of diminishing suffering as such to the greatest possible degree. Yet this is problematical. By his means the medical man preserves the life of the mortally ill man, even if the patient implores us to relieve him of life, even if his relatives to whom his life is worthless and to whom the costs of maintaining his worthless life grow unbearable, grant his redemption from suffering. . . . Yet the presuppositions of medicine, and the penal code, prevent the physician from relinquishing his therapeutic efforts. Whether life is worth while living and when—this question is not asked by medicine. Natural science gives us an answer to the question of what we must do if we wish to master life technically. It leaves quite aside, or assumes for its purposes, whether we should and do wish to master life technically and whether it makes ultimate sense to do so.[2]

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What was true for Weber at the beginning of the century remains true for us postmoderns at its close—a technologically muscular medical science possesses on its own no wisdom about when and how it should be deployed. For Weber, the tragedy of modernity was the possibility of possessing the means to "master life" without any requisite wisdom about how to do so. But consider how much better equipped we are today to deal with Weber's "mortally ill man." If this man had any foresight, then he has a "living will" instructing his physicians how to manage the end of his life. If his physicians feel that his care is futile, they are empowered to discuss with the patient, if he or she is competent, or, if not, with the patient's family, what level of care the patient wishes. One possible outcome of these deliberations is a "Do Not Resuscitate" order entered in the patient's chart. If the family, patient, physicians, and nursing staff disagree about how to treat the last days of Weber's miserable man, then an "ethics consult" can be requested. Today, there is no shortage of procedures or moral experts able to speak to the questions on which science is silent—"whether we should and do wish to master life technically and whether it ultimately makes sense to do so."

How well these procedures accomplish their intended goals, how competently these experts provide satisfactory answers to those questions on which science is silent, are important questions. But to ask them this way—as if they were merely an exercise in policy assessment—implies that if these procedures or experts were found wanting, then some others are capable of producing "better" results. In a volume such as this on social science, ethics, and medicine, there is an almost irresistible temptation to make such an argument: namely, that the problems of bioethics are better handled using an approach that is more social scientific, that pays greater attention to culture and class, power and position, gender and ethnicity, than the standard bioethical explorations of how to manage problems like Weber's mortally ill man.

However, in this essay I wish to forgo the general pleasures afforded by preaching to the choir. As much as I might enjoy demonstrating from my own research how the trained sensitivities of the social scientist improve bioethical discourse, I think

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little new is gained by the exercise, it having been carried out so well so many times by so many others. Instead, I want to ask how it is that we are even in the position of having to demonstrate what should be obvious: that social science matters to bioethics. First, I want to explore how bioethics came to the dominant position it has today for discussing a whole range of questions about medical care. Second, I want to show what a surprising development is the emergence of bioethics as an applied discipline. In so doing, I want to ask how it is that social scientists who came to many of these issues before, or contemporaneously with, those philosophers who identify themselves as bioethicists now need to mount special pleas for our inclusion in, our relevance to, and our importance for the discourse of bioethics.

LOOKING BACKWARDS

Now that there is a National Advisory Bioethics Commission, now that the Joint Commission on Accreditation of Healthcare Organizations mandates that hospitals need to have in place a mechanism for resolving ethical conflicts, now that numerous programs provide training that leads to certificates and degrees in bioethics, now that the graduates of these programs seek employment as "clinical ethicists," now that professional organizations and journals in bioethics have proliferated, now that a task force assembled under the aegis of the major professional societies in bioethics has issued a "consensus statement" on standards for "clinical ethics" practice and its practitioners, and now that over fifty academic medical centers have departments of or centers for bioethics, it is fairly simple to tell a "Whiggish" history of bioethics—one that makes not only its structural position but also its current intellectual configurations appear as both inevitable and desirable.

This history (which actually has more the structure of an "origins myth") is certainly familiar by now. Over the last thirty or so years, bioethics has been a response to a sense of crisis within the everyday organization of medicine. Some of that crisis was generated internally. Reports like Raymond Duff and Angus Campbell's classic 1973 *New England Journal*

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of Medicine article on the withdrawal of life support for severely compromised neonates after consultation with parents at Yale–New Haven Hospital took private clinical troubles and made them a public issue for the profession.[3] The crusading dimension to Duff and Campbell's discussion, the if-this-be-treason-make-the-most-of-it rhetoric, is hard to overlook:

> What are the legal implications of actions like those described in this paper? . . . Perhaps more than anything else, the public and professional silence on a major social taboo and some common practices has been broken further. That seems appropriate, for out of the ensuing dialogue perhaps better choices for patients and their families can be made. If working out these dilemmas in ways such as we suggest is in violation of the law, we believe the law should be changed.[4]

Duff and Campbell's article discussed neonatal intensive care, a rather recent and, at that time, still primitive technological development; but their essay spoke as well to all those other clinical arenas within medicine that had likewise expanded technologically, creating tensions for those now managing Weber's hypothetical "mortally ill man" that Weber himself could never have imagined. What for Weber had been problematic at a theoretical level given medicine's limited capacities in the early years of the twentieth century had now become empirically and emotionally difficult at the everyday level.

A second internalist critique appeared in the normally august pages of the *New England Journal of Medicine* when Henry Beecher published an exposé of physicians' conduct of scientific research.[5] Deliberate deception, a lack of a minimal concern with consent, sloppily designed trials unlikely to yield useful information, and overly risky protocols were among the faults that concerned Beecher. Like his colleagues at Yale, the Harvard physician had an innate faith that if problems became public, then they would be addressed. As David Rothman claims in his informative account of both the extent of and the limits to Beecher's whistle-blowing:

> He noted with more rhetorical flourish than evidence or accuracy that the "thoughtlessness and carelessness [of the researchers with unethical protocols], not a willful disregard of the patient's rights,

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account for most of the cases encountered." Armed with such a formulation, he comfortably asserted that "calling attention . . . will help to correct the abuses present." He maintained such an old-fashioned faith in the integrity of the individual researcher that, after weighing all the alternatives, he concluded: "The more reliable safeguard [is] provided by the presence of an intelligent, informed, conscientious, compassionate, responsible investigator."[6]

There is something particularly American about this melioristic faith that open communication leads to solutions. There is little to no recognition by the authors of either article that problems may be intractable; values, discordant; goals, divergent; and decisions (or resolutions), difficult.

The very same criticisms that were made inside medicine were also made outside of it. The end-of-life questions asked in the *New England Journal of Medicine* by Duff and Campbell were also posed by Elisabeth Kubler-Ross in her trade publication *On Death and Dying*.[7] The University of Chicago psychiatrist criticized the medical practice for its emphasis on managing dying through a dehumanizing technological regime that ignored death's spiritual and emotional dimensions:

Maybe this question has to be raised: Are we becoming less human or more human? Though this book is in no way meant to be judgmental, it is clear that whatever the answer may be, the patient is suffering more—not physically, perhaps, but emotionally. And his needs have not changed over the centuries, only our ability to gratify them.[8]

Here Kubler-Ross is exhibiting some of the denial that she claims is part of the first stage in adapting to a terminal diagnosis. It is hard to read *On Death and Dying* without being impressed by how judgmental it is. One of these judgments is that there is an emotionally correct way to die that crosses generations, classes, and cultural groupings. While Kubler-Ross is a physician, it is important for our purposes to note that she makes her critique largely outside professional domains and her appeals are directed as much at patients and families, who should demand better, as at health professionals, who should know better. Her account, in fact, emphasizes the obstacles medical staff placed in front of her work.

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> As described earlier, the hospital staff responded with great resistance, at times overt hostility, to our seminar. At the beginning, it was almost impossible to get permission from the attending staff to interview one of their patients. Residents were more difficult to approach than interns, the latter more resistant than externs or medical students. It appeared the more training a physician had, the less he was ready to become involved in this type of work.[9]

A few years after the public discussion on the significance of the fact that public discussion of death and dying was no longer taboo, which Kubler-Ross's work in part fueled, a series of media-intensive "right to die" cases emerged, the most important of which was that of Karen Anne Quinlan. Besides the enormous amount of coverage and, hence, collective awareness of ethical dilemmas in modern medicine the case generated, two features of it are worth noting here. First, this was not a conflict that could be resolved within the normal doctor-patient relationship. Even if Karen Anne's physicians agreed with her parents' decision to disconnect her respirator, they felt the need for legal protection and approval before embarking on this course. The structure of the legal process made Karen Anne Quinlan's parents and her physicians adversaries, which clearly showed that both the nature and the pace of this process rendered it inadequate for resolving conflict in instant cases. A considerable amount of the commentary on the case as it unfolded centered on why we are, as a collectivity, trying to solve this problem in this way. Second, this structural impasse did not escape the New Jersey Supreme Court, which, while seeing the right to die as a privacy issue, nonetheless recommended that hospitals use ethics committees to resolve such problems and thereby keep them out of the courts. Such a policy, when followed, makes private decisions more public and requires individuals willing to claim expertise in ethical decision making. It assumes as well that such expertise will serve to silence social conflict. And, to the social scientist, this expectation—that an ethics process internalized within the hospital will reduce conflict—may be the feature of clinical ethics most worth exploring.

As with death and dying, in the domain of research ethics much of the criticism made within medicine was made from

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outside of medicine. Two research projects in particular received considerable media attention. Both involved the exploitation of vulnerable populations in federally sponsored research. The first was the infamous Tuskegee Syphilis Study. This "natural history" of untreated syphilis in black males involved researchers actively preventing subjects who were poor black sharecroppers from receiving medical treatments. The subjects were never informed that they were in a research project that forbade treatment. The second project involved the injecting of retarded children at Willowbrook, a residential treatment center, with Hepatitis B in order to test a vaccine. As in Tuskegee, consent was forgone. These research abuses were not discovered by the medical profession. Rather, the fact that they were uncovered by journalists and were then the subject of legislative hearings was taken as evidence of the failure of internal reform. Those outside of medicine confronting these abuses felt, unlike Beecher, that if these ethical problems of medicine were to be faced, it would be because of pressure and resources brought from the outside. Moreover, and this seems odd in today's antiregulatory atmosphere, such outside scrutiny fit the temper of the times. There was something like a national consensus that institutional domains, such as medical practice and research, could be made more accountable only through a greater surveillance of their activities. In this spirit, medicine was one of many institutional domains subject to the antiseptic and disinfectant effects of the sunshine of public surveillance.

And, in a manner of speaking, the problems of deceitful research were faced from the outside. A National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research was formed, which promulgated regulations after holding hearings and deliberations. These regulations, when adopted, required that all institutions receiving federal funds have institutional review boards in place to monitor research protocols for the adequacy of consent procedures and of risk-benefit ratios. The National Commission was followed in a few years time by a President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research. Whatever else may be said of the work of the President's Commission, and the National Commission before it, at a very

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minimum each legitimated public discourse by nonmedical experts on problematic areas of medical practice and research. The doctor-patient relationship was now very much a public concern. The documents that the President's Commission produced serve either as informal national practice guidelines or, less grandly, as a baseline for public debate and discussion. The most recent legitimating event for bioethics has been the appointment of a permanent National Bioethics Advisory Commission. What is significant here, and in each of the preceding moves, is the public approval given to the idea that what is wrong with health care is somehow connected to ethics and that such problems are best fixed by ethicists. The entire nature of the debate inside and outside the profession has acted either to squeeze other definitions of the problems outside the arena of discourse or to force other critics to frame their critiques in terms set by bioethics and bioethicists.

LOOKING FORWARD

As I have stated, this brief sketch of the growing dominance of bioethics is decidedly Whiggish—it thinks backwards about a complex chain of events and selects for emphasis only those that make the current state of affairs seem natural, inevitable, and desirable. Of course, to tell the story this way is a distortion; more than that, it obscures first what kind of change bioethics represents and, second, how peculiar a development is the emergence of bioethics, especially as a clinical specialty.

The typical account of bioethics coming to its present position in the medical center celebrates its "transformational" or "revolutionary" impact on medical practice. The claim is often advanced that with its emphasis on patient autonomy, bioethics played a large role in overturning a regime of physician paternalism and replacing it with one that was patient-centered. Such a claim overstates how much of a challenge bioethics posed to medicine. Although at certain points the bioethicist's critique seems to be a broad indictment of medical practice, it is actually quite limited. For the bioethicist, the problem is not one of structural arrangements, the distribution of power, privilege, and authority, or the culture of medicine itself—all of

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which call for the expertise of the social scientist and suggest the need for more radical, structural change than bioethics has wrought. The problems of medical practice, as defined by bioethicists, are ones of values in a relationship. Place the right values in the doctor-patient relationship and the problems disappear. From the perspective of bioethics, it was as if everything was right with the way medicine was practiced except for what was said and how it was said in certain very exceptional circumstances. Those exceptional circumstances, the problematic beginnings and endings of life, were precisely those areas where Weber had noted that science was silent, areas where the presuppositions of medicine as science prevented the questioning of effort. Beyond that, they were areas where new technological capacities made those issues appear somehow discontinuous with their prior incarnations as "human condition problems," which medical professionals have always had to face.

If one assumption of bioethics is that the problems of medicine are located at the level of the individual doctor-patient relationship and consist of the inappropriate values operating within that relationship, then a second assumption is that bioethicists can fix or ameliorate the problem by correctly analyzing that values problem. Where this idea comes from, whether philosophers actively sold it to physicians, or whether physicians on their own promoted it, is not so critical to determine here. Rather, what is worthy of our attention is how naive the idea that ethical analysis leads effectively to ethical practice seems when stated plainly. After all, there are not many areas where we equate theoretical and practical wisdom. We have cultural myths about lawyers dying intestate, cobblers' children running around unshod, and mental-health professionals whose entire being screams for a few effective therapeutic interventions. Further, the idea that moral theory can be used to solve practical problems cuts against so many beliefs prevalent in the medical, academic, or larger political culture that we might wonder about its centrality to the bioethics enterprise. What I want to emphasize here is how odd was the idea that bioethics through moral philosophy or ethical theory had something concrete to offer the clinician.

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To do that, I want to recapture a sense of the medical and academic environment as I thought it existed the first time I heard the word *bioethics,* on the first occasion I heard someone introduced as a bioethicist. The time was the spring of 1974; the occasion was a symposium on Ethics, the Law, and Abortion at the University of Chicago Law School; and the speaker was Daniel Callahan, who headed up an organization I had until that moment never heard of—The Hastings Center of something or other (I did not catch at the time the longer, proper description of the organization, and I was certainly unaware that my private trouble correctly recalling that longer title was to become something of a public issue). At the time, I was a graduate student doing fieldwork in surgery—I certainly would not have identified myself as a medical sociologist. In fact, I am certain that I did not yet realize that sociologists were categorized by their research interests or methods. Looking back, I wonder now what attracted me to the symposium. The University of Chicago had an unquestionably rich schedule of intellectually stimulating gatherings, but I was in the last lap of my graduate work and not easily coaxed away from my tasks. But there I was.

I do not remember much of Callahan's talk save for his brief definition of bioethics—the application of ethical theory to the dilemmas raised by the practice of modern medicine, especially those problems created by the application of new technologies—and my reaction, which was swift and savage, balanced somewhere between hostility and incredulity. If I had ever heard a nonstarter of an idea, this was it. This reaction was not just the hostility to philosophical speculation that had been part of my sociological training; this was more than the standard injunction to concentrate on what is and avoid speculation about what ought to be, although the repetition of that part of a social scientist's credo must have exercised some impact. No, this reaction was based on my understanding of medical culture from the scant fieldwork that I had already conducted. The reaction was also surprising to me in that my limited observations of medicine suggested that ethical questions did indeed need to be aired.

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What I had learned living among surgeons was that to characterize an issue as "ethical" signaled a number of things. First, issues that were "ethical" were seen as issues that were not resolvable. There was no gold standard against which to measure responses, against which to credit some as correct and dismiss others as wrong. The corollary of this was that ethical issues could be debated forever with no resolution. Since surgery had an ethic of action, such debate was seen as a waste of everyone's time. My fieldwork was done in an academic setting, in a prestigious training program, as a visible observer scribbling into a small notebook, so, from time to time, attending surgeons might display their ethical reasoning either because they had been asked to, because they thought it didactically necessary, or because they cared what the observer thought of them. But the general feeling was that ethical discussion wasted time, effort, and energy—it stole time from caring for patients, reading journals, dictating discharge summaries, or practicing knot-tying. Those students who pressed ethical questions were often asked sarcastically if they wanted to be internists or surgeons. A correlate of this was that whenever I raised ethical issues in my field notes or discussions with my principal adviser, he would ask me with more than a little irritation if I were writing a dissertation or preparing for the rabbinate. So, however aware I was that ethical questions needed a fuller discussion than they were receiving, I was also aware of a general hostility toward such questions.

In general, cases that raised ethical questions were both abundant and rarely discussed. For example, during the eighteen months of my fieldwork, a young black male who had lost all but four inches of his bowel to a gunshot wound and an incompetent resident, who was on call the night this patient was rolled in, was kept alive, while an attending tried to work out in his lab some of the problems that inhibited successful bowel transplants. The patient had no idea what was going on. I never once heard the ethical dimensions of the case discussed by the entire group during rounds or any other conference; my notes only record two times when residents or students mentioned the ethical dimensions of the case and then just barely: "I wouldn't want to be kept alive like that." This is not to say

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that the case was not discussed, because it was, but always from a very narrow, technical point of view: the problems of alimentation, the inevitability of rejection reactions, the reasons the four other attempted bowel transplants to date had so decisively failed, the promising new leads in the laboratory. Nor is it to say that the attending in question did not consider the "ethics" of the case. I am certain that he did—he was an unusually thoughtful and reflective person—he simply did not "share" his thoughts with the group. And this lack of sharing was itself important: it indexed a primary belief about ethics. With authority went responsibility—ethics were personal. Attendings had an unquestioned and, at the time I did my observations, socially unquestionable decision making authority. There were decisions that "only an attending could make." Little was gained by public debate of such situations. Young apprentice surgeons were taught that there were tough ethical decisions, that these were personal, that they need not be discussed or reflected upon in an open forum, and that making such decisions was a prerogative of rank. They were in training so that when their time came they would not flinch before this burden. A suggestion or proposal that a patient or a nurse might question a surgeon's handling of a case or that they had the capacity to have that handling reviewed by an ethics consultant or an ethics committee was Swiftian in its preposterous implausibility.

Now I suppose that since I knew that surgery was not the entire world of academic medicine, that there were strong cultural differences between surgery and internal medicine, and that in internal medicine there was a higher tolerance for both discussion and "theoretical" issues, I should not have been so quick to dismiss bioethics as a doomed enterprise. But I had noticed that when surgeons and internists disagreed about patient care, those disputes were resolved by figuring out whose patient it was. Both surgeons and internists seemed to agree that ethical decisions were reserved for the physician in charge. Further, I had, by that time, attended a few joint internal medicine-general surgery conferences on the management of the terminal patient. From the sentiments expressed in those meetings, I could see no differences in the decision making

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prerogatives given to the physician in charge. I could not help but notice that there was less hierarchy in internal medicine. This meant that residents in internal medicine had to arrive at their own personal philosophy or ethics of care much sooner than residents in surgery, who were often shielded from such issues as they perfected their technical skills. Looking back, what I now see, but did not realize at the time, is that residents in internal medicine, who were left so alone with such weighty questions so early in their careers, would find the help bioethicists promised attractive. Certainly, a major recurring theme of the first-hand narratives of physicians who trained during this time period is that the steady hand and cool reason of a more seasoned authority is absent.[10] The texts fairly scream with rage at how much the physician in training has been abandoned, at how little guidance is provided for such complex human-condition questions.

There were two other reasons why I thought, while listening to Callahan, that medicine was not likely to find bioethics attractive. First, I did not observe that physicians were receptive to the collateral expertise of other professionals. Callahan was defining a substantive domain in which philosophers could provide physicians with help. I could not help but notice that the physicians I was observing had some trouble asking for help with ethical or, for that matter, any other sorts of problems. It was a difficult enough matter to get the surgeons to consult already established services appropriately rather than ignore them. Medical social workers were consulted only when there were obvious discharge problems. Psychiatric liaison was seen as a distasteful last resort, often used when the importunings of nurses made it impossible to stall any longer. The input of nurses was very rarely sought; when offered unsolicited, it was listened to more as a tactic of keeping social peace than because it promised to be useful. And while all this may seem either to be exaggerated or to be just an indicator of surgical boorishness, I thought about it differently. If those with training, clinical experience, and an established place in the hospital hierarchy were not taken seriously, then I did not see how it was possible that outsiders, namely, bioethicists, would establish a foothold. Here, what I missed was the role physicians with an

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interest in medical ethics would play in sponsoring the concerns of bioethics and bioethicists.

Next, there was something about the "values talk" of bioethicists that I thought would not play well in medical domains. The ethical problems that I had observed—that is to say, those problems that were openly recognized and categorized as ethical (there were ethical problems aplenty that never got so labeled and were, as a consequence, never viewed through the lens of ethics)—cried out for immediate solutions. These cases were, as I viewed them as a fieldworker, mired in contextual details often so different from case to case that I could not imagine any set of values or principles so flexible that they would permit generalization across cases. I thought, quite wrongly, that whatever an approach grounded in ethics had to offer, it would be so abstract that physicians seeking guidance would only experience frustration. After all, I could not help but notice how relentlessly empirical physicians were—rigorous positivists, they scorned nothing so much as data that were "anecdotal" or explanations that were "speculative." Again I was wrong and it is easy to identify why. I did not appreciate how compatible the thin sociological description of the medical case was with the thin sociological description of the philosophical one. In each case, the thinness served a purpose: the physician was able to concentrate on pathophysiology; the philosopher, on principles. Neither needed to deal with the variety of ways in which the social context muddies the waters. In addition, I did not appreciate how the conceptual flexibility of the philosopher's principles served the physician seeking legitimation for a course of action. Action and principles needed only be described in ways that emphasized their fit. The more general the principle, the easier the task. So what I saw initially as burdens to the adoption of bioethics turned out, on closer inspection, to be benefits.

Those were the obstacles that occurred to me at the time, and they seemed sufficient to stop any further exploration. I had good reasons for expecting bioethics to fail to take root in the academic medical center. Had I the need to find additional reasons to predict the failure of the "bioethics project," I would not have needed to look very far. Three additional disabling

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factors suggest themselves. First, the role being proposed for bioethics and bioethicists was one that was increasingly out of favor among academic moral philosophers. After all, a major selling point of bioethics within the medical center was the ability of moral philosophers to provide a problem-solving methodology for the vexing day-to-day troubles of modern medicine (of course, not all those involved in bioethics promised this). The dominant approach, in the field's dominant text of principlism, seemed to offer a shortcut for reasoning through some difficult troubles.[11] Principlism, which was not without its critics, is alluring because it is not only comprehensible but appears easy to apply and, thus, removes from ethical questions the earlier stigma conferred by their being unresolvable. But it was just this claim that ethical theory had direct problem-solving capabilities that was being widely rejected within academic philosophy.[12]

This schism between the applied philosophers in the medical center and the theoreticians of the academy had, however, little impact on the recruits to or the development of bioethics. One reason is that medical centers had resources at their disposal that philosophy departments did not. Bioethics programs, institutes, and centers were started within medical centers, and some journals were underwritten there. Whatever academic philosophers thought of all this, whether they thought that the ethics that medicine had saved the life of was worth saving,[13] mattered little in the face of the resources medical centers commanded. If academic philosophers disapproved, then bioethics programs in medical centers would train the personnel needed as ethicists. If the prestigious journals in philosophy were uninterested in the applied questions on which bioethicists wrote, then there were new outlets for such writing aplenty. All of this means that bioethics developed within the institutional structure and with the institutional resources of academic medicine, and this undoubtedly influenced its critical thrust. At the same time, the fact that its oldest and best known institution, The Hastings Center, was free-standing helped sustain an illusion of the field's independence. It meant as well that this branch of applied ethics could safely ignore, or dismiss as sour grapes, the criticisms of colleagues in academic departments.

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Not only was the field of bioethics with the bioethicist in the role of clinical ethicist contrary to currents within academic philosophy departments, but the framework of principlism that guided so many of the day-to-day applications of bioethics was itself out of step with trends in the surrounding culture. Advocates of principlism suggest that the application of four values—autonomy, beneficence, nonmaleficence, and justice—is sufficient to resolve ethical problems as they arise in the clinic. This is not the place to rehearse the criticisms of principlism, the defense of those criticisms, the revisions of the original formulations, or the modifications that allowed principlism to gear into the world as a guide to action. Here, I want simply to call attention to leading assumptions of principlism: namely, that the individual is the proper measure of all things ethical, that tools for measurement transcend culture, and that there is a single, correct solution for each ethical problem, which is largely independent of person, place, or time. At the time that this ethical universalism is gaining ascendance in the world of medicine, it is being rejected in virtually every other sphere of society. In academia, cultural relativism had made the assertion of a single ethical standard applied across cultures highly problematic. In the public arena of political culture, the spirit of cultural pluralism made the assertion of such a single standard not only unfashionable but also a badge of great insensitivity. The fact that bioethics embraced principlism and that this embrace took root in such a complex community as the modern medical center is peculiar, to say the least. Of course, the very nature of principlism gave it a curious dual aspect. On the one hand, the four principles seemed to provide something like a moral methodology for public discussion of ethical issues. John Evans has even suggested that principlism functions in ethics much as double-entry bookkeeping does in accounting: it makes commensurable what was formerly incommensurable.[14] On the other hand, despite the seemingly privileged place of autonomy, the fact that principlism allows the four principles to be combined and deployed in any configuration allows a wide range of cultural preferences legitimation under its aegis.[15] Principlism has then the seeming advantage of being both authoritative and sensitive to cultural difference.

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Finally, bioethics had to struggle against a resistance to rule by experts in American society. The questions that advocates for bioethics felt most comfortable addressing were almost exclusively questions of "bedside ethics." However, here one might ask why the paternalistic judgment of one expert should be replaced by that of another. Further, the basis of granting legitimacy to the physician was grounded in a long-standing cultural logic. This was not so for the moral authority of the bioethicist, which was being created on the spot. The fact that bioethicists spoke of what they were doing as restoring power to patients obscured the power they needed to abrogate themselves to accomplish this task. It also obscured how much patients actually desired this decision-making power now conferred upon them. It is worth noting in this light how rarely the resources for a more muscular assertion of patient autonomy are utilized.

A TEMPORIZING CONCLUSION IN THE PRESENT

I have tried to sketch how bioethics ascended to its current dominant position and to give a sense of the many cultural obstacles it had to overcome in doing so. I probably have not conveyed as clearly as I might how, all of the above notwithstanding, bioethics was a response to deeply felt needs within both the medical community and the larger society. In concluding, I want to turn to the task that I eschewed at the beginning of the essay—defining where social science might fit into the bioethics project. But the prolix prologue to what will be a spare set of conclusions is in some sense a demonstration of the major role that the social sciences play within bioethics: the provision of context, the gentle insistence that principles are attached to persons, and the constant reminder that those persons have interests, a history, and a culture. Three examples will suffice to sketch the role for the social sciences that I have in mind, to show the difference that richer contextual accounts make.

First, now that bioethics has some institutional anchorage and cultural legitimacy, a number of histories of bioethics have emerged. These accounts are somewhat triumphalist in tone,

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seeing bioethics as a victory of patients over medical authority. These histories associate the rise and ultimate success of bioethics with the success of rights-based movements more generally. The account of bioethics' rise to prominence offered here tempers this triumphalism by showing how limited was the challenge presented to organized medicine. Had space permitted a fuller discussion, I would have shown that bioethics was a contemporaneous alternative to a more forceful challenge to medicine spearheaded by consumer and patient activists. This later challenge was more confrontational in tone, more insistent on structural change, and more focused on the politics of health care than was the bioethics movement. By assimilating bioethics, organized medicine was able to defang this other, broader challenge. Even without a full discussion of this alternative to bioethics, my account stresses the interests that were involved in bioethics coming to the fore and emphasizes the fit of bioethics with academic medicine. This is not to say that bioethicists' claims that they have provided patients a greater voice in determining their own affairs are incorrect. It does provide data, however, to allow us to question whether those changes are as dramatic as their promoters would have us believe. Also, by pointing out how bioethics' triumph is related to how limited was its challenge to organized medical interests, we are also in a position to understand why bioethicists have not raised a number of political issues that also can be defined as ethical questions: the presence of so many millions of Americans without health insurance, the multiple ways the production pressures of managed care undercut the possibilities of the doctor-patient relationship that bioethics celebrates, the inequalities in health status between rich and poor, or the replacement of professional values with corporate ones.

Second, we social scientists provide just the kind of context bioethicists so often obscure when we produce ethnographies of medical settings that describe as thickly as possible how ethical problems are ignored, unattended, recognized, managed, and resolved in medical settings. There are good recent examples in which ethical problems in the medical workplace are a focus of the analysis.[16] But the goal is not to show how these problems are properly or improperly resolved. Rather, the focus is on

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how the problems are structured. These examples show first how problems in the workplace of the hospital come to be seen as ethical, and then what this labeling accomplishes in term of conflict management. In each work, problems that an earlier period would have addressed as problems in the organization of work, the division of labor and responsibility, and the structure of authority are now labeled as ethical. This labeling allows power differentials between the ranks of doctors, nurses, and patients to be effaced. It also allows a hearing for the nurses' and patients' perspectives on what should be done, which would not happen unless the problems were understood as "ethical"—a domain that bioethicists assume operates outside of the social structure. By bringing the context of dispute into the bioethics discourse, social scientists deepen our understanding of the ethical conflict and question the assumption that the right thinking with the right values will suffice to silence the conflict.

In a very real way, if ethnographies of medical settings are properly done, they may very well cut against the objectives of bioethicists. There may be a built-in incompatibility between bioethical and sociological inquiry, and heightening this tension rather than attempting to deny it may very well be a useful contribution of the social scientist to bioethics. The purpose of bioethical inquiry, I assume, is to clarify which principles should guide action when decision is difficult. In bioethics, descriptions of motives, intents, and purposes need to be fairly one-dimensional or the balancing of values gets too complex for application. The goal of social science, especially as practiced by ethnographers (again, this is my assumption), is to show how actors shape and trim their actions to fit their principles and how these same actors shape and trim their values and principles to fit their actions. Where bioethicists seek clarity, social scientists look for ambiguity and complexity. Social scientists are eager to show that our subjects are not slavish followers of rules, that they are not in principle or action "judgmental dopes,"[17] but that they have great flexibility in deciding which rules to apply and when to apply them. If one thinks about this, this is a message at odds with the goals of bioethical analysis: identify a situation correctly and decide what principles apply, and ethical behavior will follow. These premises are implicitly

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challenged by ethnographic accounts. Clarity about values for the social scientist is very seldom a reassurance that any specific behavior will occur in the next instant. Social scientists are more sensitive than bioethicists to the well-known lag between values and behaviors. A contribution that social scientists can make and remake to bioethics is a close inspection of the fit between what we do and what we say we are doing—our actions and our intentions.

Finally, social scientists can contribute to bioethics by studying this discipline. When sociologists are invited into bioethics, aid is sought for pre-identified problems. We social scientists are invited to join the team. Flattering as this invitation is, social science may aid bioethics more by declining the offer. (This, I realize, may read somewhat disingenuously; it is being written, after all, by someone with a faculty appointment in a Center for Bioethics. But, in my own defense, let me say that ethnographers have long realized that the proper balance of nearness and distance is difficult to achieve.) Bioethicist is a new role, and we know very little of how it works in the everyday medical contexts of its use. What do bioethicists do? For whom? Under what conditions? We need to contextualize bioethics itself and see it as an object of study. We have done precious little of this. And plainly we need to do more. How are bioethicists trained? How do those in the field define their domain of responsibility? How is orthodoxy established? How is dissent managed? These are beginning questions. In asking them, we need to ask broader questions as well. How is moral authority constructed and legitimated in the case of bioethicists? How is the role and moral authority attached to it connected to an increased concern for ethics in other societal domains? Social scientists have contributed and will continue to contribute to our understanding of many of the substantive problems in the domain of bioethics. These contributions, however, should not blind us to the contribution we have yet to make: the description and analysis of the everyday work of people in the new social role we now call bioethicist.

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ENDNOTES

[1]Personals' advertisement, *The Nation*, 13 June 1994.

[2]Max Weber, "Science as a Vocation" (1919, 1922) in H. H. Gerth and C. Wright Mills, eds., *From Max Weber: Essays in Sociology* (New York: Oxford University Press, 1946), 144.

[3]Raymond Duff and Angus Campbell, "Moral and Ethical Dilemmas in the Special Care Nursery," *New England Journal of Medicine* 289 (1973): 885–890.

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[5]Henry Beecher, "Ethics in Clinical Research," *New England Journal of Medicine* 274 (1966): 1354–1360.

[6]David J. Rothman, *Strangers at the Bedside: A History of How Law and Bioethics Transformed Medical Decision Making* (New York: Basic Books, 1991), 83–84.

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[12]Bernard Williams, *Moral Luck* (Cambridge and New York: Cambridge University Press, 1981); Stuart Hampshire, *Morality and Conflict* (Cambridge, Mass.: Harvard University Press, 1983); Alasdair C. MacIntyre, *After Virtue: A Study in Moral Theory* (Notre Dame, Ind.: University of Notre Dame Press, 1981); and Michele M. Moody-Adams, *Fieldwork in Familiar Places: Morality, Culture, and Philosophy* (Cambridge, Mass.: Harvard University Press, 1997).

[13]S. Toulmin, "How Medicine Saved the Life of Ethics," *Perspectives in Biology and Medicine* 25 (1982): 736–750.

[14]John Evans, "Max Weber Meets the Belmont Report: Toward a Sociological Account of Principlism," paper presented at "The Conference on the 20th Anniversary of the Belmont Report: Past and Future Directions," University of Virginia, Charlottesville, Va., April 1999.

[15]Paul Wolpe, "The Triumph of Autonomy in American Bioethics: A Sociological View," in Raymond DeVries and Janardan Subedi, eds., *Bioethics and Society: Constructing the Ethical Enterprise* (Upper Saddle River, N.J.: Prentice Hall, 1998).

[16]These include Renee R. Anspach, *Deciding Who Lives: Fateful Choices in the Intensive Care Nursery* (Berkeley: University of California Press, 1993);

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Charles L. Bosk, *All God's Mistakes: Genetic Counseling in a Pediatric Hospital* (Chicago: University of Chicago Press, 1992); Daniel F. Chambliss, *Beyond Caring: Hospitals, Nurses, and the Social Organization of Ethics* (Chicago: University of Chicago Press, 1996); Renée C. Fox and Judith P. Swazey, *Spare Parts: Organ Replacement in American Society* (New York: Oxford University Press, 1992); Carol A. Heimer and Lisa R. Staffen, *For the Sake of the Children: The Social Organization of Responsibility in the Hospital and Home* (Chicago: University of Chicago Press, 1998); and Robert Zussman, *Intensive Care: Medical Ethics and the Medical Profession* (Chicago: University of Chicago Press, 1992).

[17]Harold Garfinkel, *Studies in Ethnomethodology* (Englewood Cliffs, N.J.: Prentice-Hall, 1967).

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Arthur Kleinman

Moral Experience and Ethical Reflection: Can Ethnography Reconcile Them? A Quandary for "The New Bioethics"

REMAKING THE CASE FOR BIOETHICS

WITH HASTENING PACE, bioethics in America is moving in manifold ways to deal with serious problems in its *modus operandi.* These problems have become so well known they are by now clichés. In previous studies I have attempted to characterize them by means of three "isms": ethnocentrism, medicocentrism, psychocentrism.[1] By this awkward-sounding trio I meant to encompass past criticism of bioethics on account of its Eurocentric orientation and grudgingly limited engagement with non-Western and ethnic value orientations. I also meant to conjure its tendency to prioritize often esoteric professional formulations over ordinary, commonsensical patient and family perspectives, as well as to critique the way ethicists psychologize moral issues that in everyday life are more often expressed by ordinary people via religious, social, and somatic idioms. Others have so flayed the principle-based methodology still in command today that this

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mode of criticism would be pointless were it not for the persistence of a rather narrow Anglo-American analytic philosophy as the discipline's canon. The discipline itself has made many moves (at least in America) to apply, or respond to, survey research, clinical epidemiology, ethnography, cultural studies, narratology, feminist theory, and still other contextual methods of analysis and engagement. And neopragmatism and continental philosophy are making some, if limited, headway, even if social theory is still held at a distance. So much is changing so fast that we might well speak of "the new bioethics": more inclusive of alternative approaches, seemingly more willing to employ a broader variety of perspectives, more empirical, and even experimental—in the sense of trying out, albeit gingerly, new methods of inquiry.[2] One must recognize, of course, that this is not (at least not yet) the dominant stream of bioethics, that it is "new" only in the sense that ideas that have been around for some time are now being more widely embraced.

For all these efforts at repair and reform, however, bioethics is confronted with an extraordinarily difficult quandary: how to reconcile the clearly immense differences in the social and personal realities of moral life with the need to apply a universal standard to those fragments of experience that can foster not only comparison and evaluation but also action.[3] For philosophers, the gulf between the universal and the particular may be regarded as an irksome and a perennial barrier; but bioethicists, like clinicians and policy implementers, simply cannot function without finding a way of relating ethical deliberation to local contexts.

The issue can be put in other terms. For almost all of us, everyday life experience in communities and networks—no matter how influenced we are by global forces of communication, commerce, and the flow of people—centers on *what is locally at stake.* What matters most in the mundane and extraordinary transpersonal details that bind and define us through relationships, work, and the close politics of a particular place is the overwhelmingly pragmatic orientation of men and women everywhere. Even the quest for transcendent meaning needs to be understood in this light. The "local" nowadays may be better understood as more like a network than a neighborhood;

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yet its power to engage us in what matters continues to define human affairs. There is great diversity in what is valued, to be sure; but that ordinary people, even the marginalized, are stakeholders in local worlds is what social life is about. Status, material resources, relationships of exchange, survival, identity, and transcendence are examples of the things that are sought collectively and individually. What is at stake may differ, but the human experience of pursuing such goals is empirically describable. And that is the point: empirical research can provide knowledge about local worlds of experience—knowledge that is useful, even essential, for bioethics.

There simply is no getting around the great influence of these local moral processes. Why moral? Because they consist of the contestations and compromises that actualize values both for collectives and for individuals. Indeed, the individual-collective dichotomy is overdone; within these social processes values are negotiated and reworked among others in a space that is thoroughly intersubjective.[4] Think of the adult children of a father with Alzheimer's Disease whose dementia is so severe that he cannot remember the content of his children's statements about the question of his placement in a nursing home. The experience of suffering is lodged as much in the emotions (sadness, grief, frustration) of the children as in those of their father; indeed, these emotions build on each other. The responses that lead to decisions about when and where to be institutionalized are moral engagements within this family's relationships. They are part of ongoing conversations and exchanges that began even before these adult children were born, developed in ways inseparable from their own trajectories, bled into their actual situations at a particular time, and will without question go on after their father's death. It is not individuals as isolated beings who make the choice to place a parent in a nursing home, *pace* the primal and somewhat atomistic scene favored by analytic philosophers. It is rather the person as part of a network of relations, memories, current pressures, and uncertain prospects, and constrained by interconnections and shared fate, who is the locus of moral experience. Hence moral experience is about the local processes (collective, interpersonal, subjective) that realize (enact) values in ordinary living. These processes cross the

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boundary of the body-self, connecting affect and cognition with cultural meanings, moral norms and collective identity with sense of self. Thus moral experience and personal experience are interfused: value with emotion.

Modeling ethics as a person's individual choices, which in turn are supposed to be based in deep, philosophically and psychologically informed reflection shaped by religious and secular standards that seek universal application, simply does not account for the social processes of moral life. Those processes illustrate how the person is located in economic, cultural, kinship, friendship, and work activities that powerfully define his or her moral horizon in ways of which he or she is likely to be only partially aware. In the end, then, ethics, once framed as models of moral reasoning championing the reflection and rational choice of autonomous individuals in quest of objective standards, risk irrelevance to the almost always uncertain circumstances and highly contextualized conditions of human experience.[5]

The irrelevance of ethics can be seen when considering universal ethical formulations of justice and equity that do not begin with the local moral conditions of poor people, those experiencing the systematic injustice of higher disease rates and fewer health-care resources because of their positioning at the bottom of local social structures of power. Dealing with issues of justice in the absence of these contextual concerns renders ethical formulations mere speculations, utopian pronouncements that are gratuitous and beside the point. Consider, for example, the fact that bioethics generally regards informed consent an overriding ethical condition of international health research—say, in vaccine trials for HIV among impoverished African villagers. Of course, few villagers are likely to be literate or possess knowledge of randomized controlled trials, placebos, or perhaps even conceptions of individual autonomy in deciding about participation in a community-wide activity. Yet even when attention is devoted by bioethicists to these issues, they demonstrate surprisingly little understanding of local cultural realities, and even less appreciation of the dire effects of the global economy in deepening villagers' poverty and suffering by means of structural-adjustment programs that tend to inten-

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sify local conditions of inequity and render most Africans without any hope of even minimal health-care services to treat AIDS. Then application of the "ethical" in the local setting of the "moral" must be highly suspect.

And yet can there be an understanding of ethics—in the sense of, at the very least, an imagination of and struggle to develop universal values—that does not seek to transcend the local? After all, local worlds—as in the recent examples of Bosnia, Kosovo, and Rwanda—can be utterly unethical.[6] How could we make the case for human rights and against genocide in such terrible instances based on something called ethics—unless ethics provides translocal values that can criticize local practices from the outside?

And this is the quandary, is it not? Bioethics requires *both* approaches: it must possess a method for accounting for local moral experience and a means of applying ethical deliberation. But it is unclear how this pairing of what so often seem like opposing approaches can be accomplished, or, for that matter, whether the combination inherently requires more than current concepts and methods can achieve. It is not only the limitations of analytic philosophy that create problems for bioethics in this regard; biomedicine's reductionistic paradigm also encourages blindness to this issue—as does the passionate commitment of certain social scientists to a rather superficial version of universal human rights.

BLIND ALLEYS

A classic means of approaching this quandary is to invoke the idea of *human nature*. Contexts may be as different as a burnt-out street in inner-city Harlem and a gated community of great wealth in a distant suburb of Denver, or, for that matter, the unpaved, rutted tracks of a Tanzanian village and the boutique-lined streets of the trendy Left Bank in Paris, *but* (the operative word here) ethical standards can be applied in each case because a shared human nature assures that, regardless of context, humans will universally bear the same moral sensibilities. What is more, that same shared *nature* assures that agreement can be reached *objectively* concerning what choices and actions

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should be undertaken to accomplish ethical ends. In other words, by naturalizing human experience, ethics can be predicated on a universal psychobiology, which can be objectively known.

There is only one small problem with what otherwise seems an ideal way to ground the perplexing multiplicity and inexpediency of experience in a universal feature of bodies and selves; regrettably, there is no agreement on what human nature is.[7] Speculation changes from era to era and from theorist to theorist. Not only cultures, but religions, ethnic groups, legal systems, medical institutions, age cohorts, and research discourses disagree on what is held to be universal; what within that set is determinative; and which features of the person are biologically endowed, which are socially shaped, and (in each case) to what degree. Notwithstanding the immodest claims of evolutionary psychologists and sociobiologists, little that we know from neurobiology or cognitive studies provides a serviceable understanding of what is decisive to human nature as a basis for understanding the sources and consequences of particular values.[8] It is not that we lack knowledge about psychobiology; quite to the contrary, much is understood about the molecular pharmacology of neurotransmitters, the brain mapping of attention, and the psychophysiology of stress and memory. What we do not possess is psychobiological data that contribute in a nontrivial way to understanding remorse, regret, compassion, endurance, betrayal, or any other moral condition. Appeals to human nature are, like appeals to political will, no more than graceful camouflage for disguising awkward ignorance. Both are proverbial black boxes, convenient fictions that can be made to represent very different things.

We enter another, closely related blind alley in the case of claims made for an evolutionary perspective on human values. History, what we make of the past, is human time—warm, even burning narratives of meaningful experience. Evolutionary time is of another order altogether: cold, immensely remote, prior to history, and thus prior to any analyses that could tell us about value conflicts and transformations. Shards tell archaeologists how to reconstruct pots, and those artifacts in turn suggest how to interpret stylistic change. We can imagine the change in bones and muscles of ape-like ancestors, but of their ethical

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orientations, it is hard to see how we can know anything specific—to say nothing of what such ideas might have to do with us today. There are no early ancestors of man who exist today, and today's hunter-gatherers, even the most remotely located, are neither remnants of the evolutionary past nor pristine evidence of what humans were like forty thousand years ago and more.

We possess no historical or cross-cultural evidence supporting the hypothesis that ethics evolves, although an earlier era of racial "science" and eugenics posited invidiously that Europeans, Asians, and Africans occupied higher and lower rungs on the evolutionary ladder, respectively—and that they were to be valued accordingly. Similarly, the claim that ethics "evolves" is a pretense based in a knowledge that we do not (and cannot) possess.

A third cul-de-sac is the employment of such a radical relativism that the aspirations for crafting and applying universal (or at least translocal) standards is denied as illegitimate on the argument that no local world, no matter how troubling its practices, deserves to be judged by standards beyond its own. This way madness lies, because it is a dangerous misunderstanding of what comparative epistemology and ethics are about. Most anthropologists, it seems to me, hold a highly constrained relativism that insists local practices must first be understood in their own terms. But eventually that knowledge must be translated into translocal frameworks if it is to be understood in anthropological (or any other translocal) discourse. More than this act of translation, placement of such knowledge in a comparative framework assures that judgments (including criticisms) will be made. What a constrained relativism insists on is that the focus be more toward a final than an initial comparative gambit, and that an equally robust effort be made to relate those external critiques to the internal criticism already evident in a given local world—which may have the result of lending strength to those critiques in the give-and-take of local contestation and resistance. But that respectful search for internal warrants to support external perspectives should not lead to the truly dangerous abdication of the burden of

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responsibility for providing translocal judgment on what is locally at stake.

A WAY OUT OF THE WOODS?

There are potential ways of connecting moral context with ethical reflection. The writings of social historians, biographers, experts in the social study of religion, feminist theorists, narratologists, cultural-studies scholars, interpersonal psychotherapists, and phenomenologists suggest different ways of getting at the issue. So, too, do the writings of novelists and dramatists, who are highly observant of how individual lives reflect the tensions and coping patterns of an era. Of all these tools, that with which I have had the most familiarity is ethnography. So I will here use ethnography to illustrate how the central question facing the new bioethics might be handled as part of the effort to rethink and reframe the relationship of ethics and social context.[9]

Ethnography is not new to bioethics. In 1992, Hoffmaster initiated a call for an ethnographic mode of doing bioethics that has found an audience especially among clinicians.[10] In fact, there is at present something of a bandwagon for ethnography in bioethics. It is fashionable to "do ethnography"—though much of what is written discloses not so much serious training in this research approach, but rather a studied indifference to how anthropologists and sociologists have conducted ethnographic field research. Nor is ethnography to be romantically regarded as a straightforward methodological solution to thorny and controverted theoretical questions. Indeed, as recent debates in anthropology illustrate, ethnography itself has limits both as a research method and as a means of reworking theory. Moreover, it has undergone considerable change in recent years, to an extent that what falls under this category needs to be critically examined in light of an impressively diverse literature.[11] Anthropologists, of whom a small but increasing number are working in ethics, of course have made ethnographic inquiry a crucial *modus operandi* for their work in bioethics.[12] Hence, I pretend to no originality here. My purpose is rather to

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inquire how far one can take the model of ethnography as a means of addressing the bioethicist's dilemma described above.

Ethnography is a method of knowledge production by which the ethnographer enters into the ordinary, everyday space of moral processes in a local world. The ethnographer, no matter how successful she is in participant observation, either is or becomes an outsider—even if she begins as an indigenous member of the community she studies. She feels the tug of local obligations and the push of local practices, but for all of that she is never so completely absorbed by what is most at stake for community members that their world of experience is entirely hers. Her engagement is always subverted by her inner awareness of her separation from those around her because of her task (description and interpretation of the lifeways of others) and her interests (scholarly and personal). In fact, she may well feel the undertow of currents in her own local world ("at home") as yet another source of separation. In this respect, the ethnographer's position bears a resemblance to the circumstances of those who either belong to several distinct worlds or identify themselves as marginal to the mainstream. Since part of this crucial positioning is her engagement with a social-science discourse that is translocal, the ethnographer, at the very least, is involved with global processes that not only differ from but require juxtaposition with those around her. It is this positioning that makes ethnography the very model of the predicament confronting bioethics. Hence, how ethnographers resolve this tension should be instructive.

The ethnographer's angle of exposure does convey, however, one large advantage. It places her, not unlike the clinician, so uncomfortably between distinctive moral worlds on the one side, and local and global ethical discourses on the other, that she perforce becomes—at times, it would seem from published accounts, even against her own will—self-reflexively critical of her own positioning and the commitments and problems it entails.[13] The sheer tension destabilizes stereotypes and clichés and makes her attentive to the original and unexpected possibilities that can (and so often do) emerge in real life. And ethnography is caught up in the requirements for practical action, even if it all-too-regularly fails to offer practical solu-

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tions. For this reason, ethnography represents a heuristic to think through the bioethicist's dilemma.

The situation is clearest with respect to the local moral processes of everyday social life, which could be said to be the actual stuff (the subject matter) of ethnographic inquiry, even if many ethnographers have used other names or categories to deal with them. Hence, for example, when an ethnographer describes the flow of gifts in a local Chinese village as part of the structure of connections in family, friendship set, and community, a structure that in turn enables getting an individual's practical objectives accomplished through a sanctioned sociocentric process, she is getting at the functioning moral categories and processes of everyday life.[14] Descriptions of kinship relations, religious practices, gendered work, illness experiences, healing activities, legal disputes, material exchange relationships, and the many other facets of everyday social life illustrate the processes of everyday moral experience. Describe the threats to what is at stake for family members in an episode of life-threatening illness or the responses of workmates to a major contestation in the workplace, and you are describing the moral content and workings of social experience.

The ethnographer, like the rest of us, often takes these everyday experiences for granted, to such an extent that they become invisible, operating out of awareness. Yet the ethnographer's very marginality in the field, although professionally discomfiting and personally burdensome, enables a comparison of the moral processes she comes to understand (withstand?) by observation in her fieldwork with the moral processes that she is usually so taken up with in her own world. The dangers of social experience, which few are able or willing to see for what they are in ordinary life, can more readily be appreciated from this eccentric angle of being-in-the-world. For the ethnographer who becomes focused on this subject, the social and emotional processes are no longer outside of awareness or avoidable. Rather, the ethnographic awareness devoted to this tension highlights what I have been calling the gap between the moral (what really matters to people locally in the social processes themselves) and the ethical (the articulation of the value-based issues in a self-aware language that aspires to universal reflec-

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tion, comparison, and criticism). The former frequently troubles the ethnographer because, as we have seen, it may be unethical, while the latter, for all its claims to objectivity and universality, often strikes the ethnographer as so utterly misplaced as to threaten her with a fear of anomie—meaning, here, the demoralizing sense that there may be no norms to guide her experience.

The practice of critical self-reflection on local cultural processes (in the field and, in comparison, at home), which takes place in real time and turns on actual value-oriented interpersonal engagements, should lead ethnographers to take both indigenous ethical conversations and global ethical discourse into account simultaneously. But in fact few ethnographers formally take on responsibility for comparative ethics. Epistemology is much more likely to be their concern, even comparative and historical ontology. But this arresting irony over the limits of ethnographic practice in taking on ethics as a serious question of theory should not discourage interest in ethnography as a *modus operandi* for the new bioethics. The disciplined professional skill the ethnographer employs to get things, if not exactly right from the native point of view, at least roughly oriented to native meanings, and to understand how reality is made over in different institutional contexts through history and micropolitics, means that ethnographic description begins with a respectful understanding of local categories, local narratives, and local practices. Hence the ethnographer's data can establish ethnoethical orientations, describe contestations over what is locally at stake, and get at the relation of local and cultural orientations to global framings. Were ethnographers better prepared in ethical reasoning they would be in a nearly ideal situation to project local moral issues and actions into global ethical deliberations, and vice versa. Indeed, the ethnographer's own moral/ethical predicament itself brings the core concerns to reflection. It offers, even in its failures (which in my readings are frequent), a profound form of moral-emotional-professional autobiography. This is the contribution that ethnographers could make to ethics.[15]

A few examples of what ethnographers do and do not accomplish may be helpful in advancing appreciation of how ethnog-

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raphy might be more effectively applied in bioethics. Nancy Scheper-Hughes has described a bad-faith economy—financial and moral—in a poor and violent slum in Brazil's northeast.[16] She demonstrates with considerable eloquence that "where the threat of hunger, scarcity, and unmet needs is constant and chronic, traditional patterns of triage may determine the allocation of scarce resources within the household." The all-too-frequent result is that male heads of household, unable to find steady employment or earn sufficient wages even in the parallel economy, run away from responsibilities they cannot meet; teenage children escape through precocious and transient sexual unions or through homelessness on the violent streets; and very sickly infants, repeatedly weakened by bouts of diarrhea, experience neglect from desperate mothers who, faced with the slow starvation of even their healthy children, come to terms with the terrible awareness that not all can survive and allow the sickest to succumb so that others can live.

This deeply troubling local ethnoethical strategy of survival is explained by the ethnographer, with respect to its sources, patterns, and consequences, but it is not justified by her. The ethical quandary is deepened by her skill in balancing the terrible reality of social injustice and health inequity through which political economic and cultural processes obstruct and deform agency in the *favela* against translocal ethical criticism of what she has euphemistically (and probably oversimplistically) called "benign maternal neglect." Scheper-Hughes also finds examples of local criticism and resistance against this collective pattern of moral experience, examples that she effectively uses to anchor her own ambivalence between outrage and acceptance. The rich ethnographic description enables the reader to enter the moral space of the ethnography and to experience personally the same wrenching inadequacy in responding to the chronic tension between unethical moral processes and unavailing ethical deliberations.

Such is the considerable achievement of this master ethnographer. But her failure is also visible. Had Scheper-Hughes taken this ethical quandary as a point of departure for an effort at working out what to do in terms that were potentially generalizable, ethnography could have shaped bioethical dis-

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course. The reader is thus left with this question: has the ethnographer run up against the limits of her ethnographic imagination, or of ethnography as a tool of ethical deliberation?

Veena Das, researching political violence in South Asia, has shown how ethnic nationalism and religious fundamentalism work to prevent individual and collective acknowledgment of the suffering of victims.[17] She also discloses the tragic consequences of the state's institutional responses, through which local religious, medical, and legal representatives cover over the central moral issues, remaking the voices of victims via narrowly professional terms into something quite different from victims' demands to have their suffering acknowledged, responsibility accepted, and restitution made.

Because the moral processes that bring violence and impede repair go unaddressed, policies and programs fashioned to deal with communal violence are undercut. Das shows that until acknowledgment of the pain of victims in the local space occurs, until what is at stake for the agency of the community's members is realized, neither global ethical formulations of human rights nor political theory linking rights and duties of citizens and the state can be effectively applied. Yet even this extraordinary ethnographic description does not tell us how acknowledgment as a foundational moral act of restitution and repair can be undertaken by communities that are so divided, and whose members have routinely engaged in atrocities that deny the humanity of neighbors. If one of the most accomplished theoretical ethnographers runs up against this barrier, does it present the limit of ethnography in bioethics?[18]

Perhaps the closest we get to deriving from ethnography a practical prescription for integrating the ethical and the moral aspects of serious human problems strong enough to permit a move from description to action in bioethics is found in the writings of Paul Farmer, a physician-anthropologist (not surprisingly) who conducts both ethnographic research and clinical work among impoverished rural villagers in Haiti, slum-dwellers in Peru, and prisoners in Russia. In his new book *Infections and Inequalities*, Farmer provides what amounts to a tool box for informing practices in ethics and medicine through ethnography.[19] Combining ethnographic and clinical research

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among rural Haitians and Peruvian slum-dwellers who suffer from multi-drug-resistant tuberculosis (MDRTB), Farmer demonstrates the effectiveness of community-intervention programs for a problem that such agencies as the World Health Organization (WHO), the World Bank, and countless ministries of health in low-income societies had long since written off as untreatable. Ethnographic research sponsored an analysis of local health-care system-management strategies that were found to be inadequate owing to bureaucratic indifference and corruption. Reform of these strategies, together with the development of intensive nursing and family-support services to keep patients in demanding multi-drug treatment programs (often lasting six months to several years), produced cures and a program generalizable in other settings of extreme poverty and limited health services. The research was greatly influential in bringing about change in the strategies of both the WHO and World Bank for addressing MDRTB.

In his work, Farmer demonstrates that the ethics of social justice, health equity, and human rights only become sensible and practical in such settings of appalling human adversity when the moral lineaments of local social processes—which often serve to maintain disadvantage, inaccessibility to health resources, and inadequate treatment programs—are analyzed and responded to through the development of community services delivered within a framework combining framings of knowledge with action. Farmer builds programs that are based in the reformation of community commitments and in the remaking of global networks of responsibility. Hence, both the pharmaceutical industry as well as non-governmental organizations (NGOs) have been mobilized to reverse former policies demonstrated to be misinformed and defeating, and local families who in the past could not or would not sustain adherence to demanding treatment regimens are now doing so. Only time will show how sustainable and generalizable this approach of social medicine advocacy can be. But it is noteworthy because it is founded on the convergence of local moral processes and ethical discourse—resulting in practical means that measure up to ambitions.

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A less successful but sadly more typical result emerged from a brief study conducted by Salmaan Keshavjee, Sheri Weiser, and me of patients with hemophilia infected with HIV.[20] During the early years of the HIV epidemic in the United States, decisions were made by the blood-products industry, the Food and Drug Administration, and physicians determining that people with bleeding disorders requiring transfusion of blood products that concentrated clotting factors from hundreds and even thousands of donors should continue with these treatments—even though the Centers for Disease Control and Prevention and individual biomedical researchers warned that the blood supply was likely already contaminated with the virus responsible for AIDS. A large percentage of hemophilia patients were infected as a result—and they unwittingly transmitted the virus to spouses and children. After thousands of deaths, explicitly likened by victims to the Holocaust, patients and families were interviewed by an Institute of Medicine (IOM) panel commissioned by Congress to review the problem. The panel of experts, who regarded themselves as engaged in a scientific assessment of the "objective" evidence, were reduced to tears and speechlessness by hour after hour of the most tragic and damning testimony. Families and patients demanded acknowledgment—by the government, by private industry, and by the NGO that had ostensibly represented their interests—that they were "innocent victims" who had been wronged by collusion between policy and practice that they claimed placed concern for economic loss over concern for human loss. Their anger, sadness, and demand for justice, their call for punishment of those responsible and for compensation to victims, created a parallel moral discourse that the IOM was unable to accommodate in the text of its report. That document emerged in the unsympathetic prose of biomedicine, policy analysis, and legal procedure: a positivistic, even scientistic idiom that is taut, "hard," non-qualitative, non-humanistic, qualities regarded in the health-policy community as the most practically useful for formulating policy, and indeed as evidence of the competence to do so. Mention is made in the report's introduction of the testimonies, but other than a few minor references to them, they are largely uncommented on in the text.

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Keshavjee, Weiser, and I articulated the collective complaints as accurately as we could and interpreted them as moral representations and experiences of suffering. We did not succeed in forging an engagement with the scientific colloquy, including both its biomedical and its bioethical discourse. What we provided was a public recording of parallel yet distinctive laypersons' perspectives. But just as the lay explanatory models of causality were treated as different from the authorized scientific knowledge by the IOM committee, so too were the lay moral perspectives on suffering treated as different from the authorized bioethical version. Voice, albeit limited, was given to the hemophilia-AIDS group, but no effort was made to engage and respond to what those voices had to say, the questions they raised, or the remedies they sought.

In my experience this is quite typical of how ethnographic materials are treated in biomedicine and bioethics.[21] They are granted a place, but it is a separate and unequal place. While this practice may be defensible when the concern is the validity of causal claims (after all, biomedical science can demonstrate its comparative advantage in knowledge of causal connections), it seems highly suspect when the issue is the validity of moral/ethical claims. Bioethicists cannot demonstrate that given ethical pronouncements are more valid—what would that mean, after all?—than the moral experiences of laypersons. Our failure was our inability to persuade or to force an interaction between the voices of sufferers and those of the "ethics experts." Absent such an exchange, both bioethics and ethnography are unable to resolve the central dilemma discussed in this paper.

A much more elaborated, nuanced, and successful ethnography is Rayna Rapp's study of the social impact of amniocentesis in America.[22] Rapp, conducting research largely in New York City, worked out of a biomedical setting observing and interviewing women (and their families) in their interactions with health providers, as well as in their homes and self-help networks. She also studied her biomedical colleagues, and closely examined their and her own involvement with at-risk births, disability, and amniocentesis. The result is a multisided account of a greatly contested arena seen through the eyes of those for

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whom different kinds of things are at stake: research knowledge, clinical careers, health and disablement. Rather than a treatment that ends with ideological positioning, the close study of amniocentesis as a technology affecting real lives provides multiple narratives of what Rapp calls the "moral pioneering" relating biotechnology to the female reproductive life cycle in American society.

It is hard to imagine a more illuminating approach to such controversial issues as abortion across distinct ethnic and social class networks. Rapp describes how the charged moral processes surrounding amniocentesis are negotiated and eventually worked through. Hence, this study demonstrates how scientists, clinicians, women who undertake the procedure, and family members come together around prenatal genetic testing and its consequences in judging the quality of a fetus and whether it will or will not enter the moral community. Rapp describes as well the moral content of disability rights and reproductive rights at both local and policy levels. She examines the hybrid language—scientific and lay—within whose terminology crucial health decisions are undertaken collaboratively by players brought together in a plot authorized by reproductive technology. In Rapp's analysis, culture, gender, and power are all encompassed by the ethnographic framework. But unlike anthropological accounts of the ethics of ethnography—in which the questions turn on who is represented, who does the representing, and what are the responsibilities of voicing or silencing informants—Rapp is concerned with the ethics of the experience of reproductive technology and the life choices it creates.[23]

Rayna Rapp is an anthropologist-ethnographer for whom moral questions arise in the local context of experiences with amniocentesis. Jing Bao Nie is an ethicist-ethnographer from China who set out to study moral experiences of people in mainland China, centering on abortion.[24] Until Nie's study appeared, work on abortion in China largely centered on the meanings of abortion in the Chinese religious and ethical tradition, and on the opinions of Chinese bioethicists and physicians. Nie conducted a combined survey and ethnographic study of the lived meanings of abortion among three distinct groups:

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rural Chinese in a Hunanese village, Chinese expatriate laypersons and biomedical researchers in the United States, and physicians in China. His work shows the crucial role of gender and all it confers in Chinese society, where abortion is almost entirely an issue for women (even to the extent that some men deny that they are even aware that their wives had abortions). It also demonstrates that, *pace* the claims of China experts on behalf of Chinese—which assert a cultural master narrative supposed to represent China's 1.26 billion people uniformly—there is no master narrative, no uniform cultural position on abortion. Rather, there is great diversity among all the groups involved; some doctors, women, and families support the state's policies, while others (many others) contest and resist them, and still others articulate narratives of experiences that are complex mixes of official ideology, unique conditions, and individual agendas. Since these unofficial voices are silenced, however, owing to patriarchy, institutional dominance, and oppressive political power, Nie's account offers a view of everyday moral practices of engagement and resistance that tells a story vastly different from the official version. Yet it is the official version that is taken up in comparative discourse treating abortion in China as a foil for comparison with Western approaches.

Nie's work demonstrates that regarding ethical traditions as simple extensions of philosophical or religious traditions is an inadequate method for understanding the real cultural differences that pertain to abortion. He reveals that behind the official rhetoric authorizing induced abortion to support the one-child-per-family policy is an unofficial rhetoric of remorse, regret, and resistance. In Chinese local worlds, classical depictions of Chinese cultural norms suffer from a patriarchal bias that silences alternative and conflicting women's perspectives. Only the description of local realities—the actual contexts—provides adequate grounds to understand abortion in China today. Hence, in spite of ethnic nationalism pressing for generalizations at the level of the nation and globalization pressing for generalization of diffused and shared attitudes at the global level, Nie's research supports the main observation of this essay: notably, that moral processes experienced at the local level can be and usually are distinctive and influential. Nie

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suggests that the central issue is how to take these local narratives of experience into account. His answer to this conundrum is to interweave ethnography with ethical theory (both global and indigenous Chinese) so as to illumine serious questions about abortion in China as a political-moral-medical phenomenon. When we possess many more cross-cultural accounts of this kind, comparative ethics, based in the ethnography of local moral worlds, will be both feasible and consequential.

AN ETHNOGRAPHIC MOMENT FOR BIOETHICS

There are decidedly important limitations to what ethnography can achieve for bioethics. The first stems from the kind of scholarship that ethnography is. Ethnography is a backward-looking methodology. More nineteenth than twenty-first century, it starts with face-to-face engagements enabling both indirect participant observation and direct questioning with a small number of informants. And it takes time, a great deal of time: months and years, not hours, days, or even weeks. It requires rapport, trust, and intimacy. There is such a thing as rapid ethnography, especially in public health, but it is not a mainstream professional technique. And for good reason: ethnography requires the capaciousness of the book-length monograph to work out what its findings signify. It is thus an anachronistic methodology in an era of extreme space-time compression in global markets and in managed health care, or in requirements for knowledge production and intervention pressed on ethicists. Against such standards, it is seriously inefficient. Neither is it a compelling way to claim objectivity or to prove causality. But it does lend itself to laying out the social dynamics of ordinary experience in an (often) accessible manner, and it does offer a means of doing comparative analysis. In an era that is witnessing the hegemony of analyses based in economic, molecular biological, engineering, and (of course) legal framings of research questions, ethnography offers more than a certain quaint utility at getting at deeply human (real value-oriented) aspects of a wide range of subjects.

But ethnography is not something one picks up in a weekend retreat or via autodidactic readings. It is not simply a fungible

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methodology. It requires systematic training in anthropology (or interpretive sociology), including critical mastery of ethnographic writing and social theory; and that, too, takes time.

So how practical can it be to argue for an ethnographic moment in bioethics? In the clinical setting, the knowledge produced by this discipline seems highly appropriate for engaging the moral content both of experiences of illness, and of the professions of doctoring and nursing. That is why clinicians and clinically oriented ethicists have had an interest in ethnography. Indeed, in an earlier time I advanced an ethnographic model for caregiving itself.[25] Today, however, the dire effects on caregiving of the managerial revolution in health services and the unchallenged primacy of economic concerns, driven by the corporatization of medicine, do not encourage a sense of feasibility. Nonetheless, ethnography still seems to me appropriate as a heuristic strategy for educating medical and other health-care students about illness as human experience and about moral issues in practice. Ethnography makes unavoidable the moral requirements of doctoring, which are so easily distorted by analytic preoccupation with medicine as a business practice and caregiving as the quest for technological efficiencies. In contrast to these approaches, it describes the actual moral content of the experiences of illness and doctoring over against the sentimentalizing ideal-typical models that are now predominant.

In the complex, changing, diverse, and divisive local worlds of our era, the uneasy, divided sensibility that ethnography brings of being both within and without the flow of experience is a not inappropriate *modus vivendi*.[26] The ethnographer's self-reflective criticism of her own positioning and its limitations; her hesitancy to prescribe interventions, at least until their human consequences can be better understood; her newly emergent readiness to make a commitment not just to study others, but to engage them and to witness their problems so as to be of use (based as it would be in her acutely dismayed understanding of the failure of earlier generations of field workers to do so); and her willingness to compare local processes and non-local discourse so that they can come into relation with each other—all are relevant to the thrust of argument in this paper.

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None of this is to make the claim that ethnography is anything like a panacea or proven preventative. Yet in the absence of any ultimate guarantee of compassion and willingness to acknowledge or respond to the suffering of others—owing to the alteration of subjectivity as worlds change—the epistemological scruples, the ontological uncertainties, and the moral sensibilities (and predicaments) of the ethnographer offer themselves up as one means, limited and unpredictable though it be, of sustaining empathy and engagement that deserves serious consideration.

That is to say, the ethnographer is "called" into the stories and lives of others by the moral process of engaged listening and by the commitment to witnessing. That call to take account of what is at stake for people becomes an instructive aspect of the ethnographer's sensibility. (Or, at least, the possibility is there for this to happen, even if it frequently does not occur.) Were this sensibility to be encouraged among ordinary men and women as a mode of moral experience (and ethical reflection), would there be the possibility of a countervailing social process in our globalized times? Could it broaden the horizon of moral imagination so as to encourage engagement with the marginal and solidarity with the afflicted? The expectation of what could be achieved would, of course, need to be more limited than these possibilities, in keeping with the modesty of an anthropological intervention that amounts to rather little when put up against the driving force of political, economic, technological, and social institutional change in our disordering epoch, or the equally dangerous political, religious, and ethnonationalist fundamentalisms that have intensified in order to resist such transformation. The only thing perhaps to recommend it is that it is the only thing I can think of that emerges from (and seems valid within) my own circumstances.

Some of us have argued for such an ethnographic moment in policy and programs directed at social suffering. The obstacles to the realization of that moment are formidable; the language of policy is so powerfully controlled by economics, decision analysis, and legal procedure that it is difficult to pry open even a small space for ethnography. Nonetheless, efforts are underway to try to produce change.[27] What I am now suggesting is

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that the ethnographic approach be developed more generally as a means of teaching about moral processes and examining their practical implications. How this might be accomplished in a society such as ours goes far enough beyond the limits of this exercise to suggest that it would be most prudent to break off here with merely the barest outline of this modest proposal. Yet I do think that it may well be in the sphere of applied moral theory that ethnography, notwithstanding the usual fear among ethicists about its encouragement of cultural relativism, could well hold the most promise. Such a seeming irony would be quite in keeping with the deeply human roots and consequences of ethnographic engagement. Without relinquishing my own tendency to see the future in Weberian terms as the unfolding of newer and deeper historical tragedies, I am willing to propose ethnographic sensibility as a way of living with the challenges our era has already brought us, a way that at least clarifies the magnitude and offers a means of engaging the form of that threatening future. Of course, such a change in sensibility will amount to too little too late unless it helps to usher in new political and economic policies to address the social roots of suffering.

Nonetheless, one must also admit what a complex role the ethnographer must manage. Inherent to that role, and seemingly regardless of the ethnographer's amount of experience doing fieldwork, is a set of classical structural crises that Renée Fox, among others, refers to as phase movements from over-identification with the local world, to under-identification, and finally to crises of personal identity—the consequence of the ethnographer's resocialization in different worlds and transformation of her subjectivity in situations that can be as much occasions of personal threat as occasions for psychological growth and maturation in handling values. Ethnographers often find themselves in situations that place health and life at risk. There are distinct perils and perplexities of doing ethnography. These can lead not only to distortion and even failure in the ethnographic craft, but to inner trials of the self and suffering. Ethnographers can appropriate the voices of local actors for their own purposes and can be appropriated by them. After three decades of fieldwork I have few illusions about how

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trying ethnography is, both as professional practice and as way of being-in-the-world. So what I am recommending is difficult and dangerous as well as uncertain in outcome, like much of ordinary social life around the world.

AN ETHNOGRAPHIC METHOD

To bring the moral and the ethical together in the exigent setting of bioethics consultations—a rather narrow and highly focused application—I recommend consideration of a simple and admittedly limited method.[28] Starting in the clinical setting, this ethnographic approach might exert a broader effect on bioethics as a general way of proceeding.

- The ethnographer first clarifies vis-à-vis the issue at hand her own moral positioning in her lived worlds of work and domestic life. This is a mixture of self-disclosure and self-reflexivity.
- The ethnographer describes the particularities of the local world she has been asked to engage. She does so by setting out three sorts of knowledge: (1) knowledge of what is locally at stake for stakeholders concerning the particular instances of health, suffering, and health care under consideration; (2) knowledge of how local parties use indigenous or global ethical framings to understand these moral processes in their own world; and (3) knowledge of how the ethnographer herself applies ethical categories to the issue at hand locally.
- The ethnographer, as the instrument of interpretation and comparison, then triangulates across these different forms of knowledge to set out a framework for understanding how the intersection of moral processes and ethical discourse in this particular world defines the local human conditions of health equity and the local human consequences of health rights and responsibilities. The ethnographer should not seek a determinative understanding, which usually is illusory and can itself become an obstacle to a serviceable understanding that sustains engagement, but

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rather should emphasize the process of soliciting and engaging multiple perspectives as the most valid means of relating internal and external approaches.

- That processual framework, with its specific implications for policies and programs, then becomes the grounds for community-wide conversations between stakeholders (e.g., laypersons and professionals), out of which will emerge an agenda for practical action. At each level, the ethnographic task is to encompass and incarnate both agonistic and antagonistic framings. It is not the ethnographer's responsibility to resolve these tensions, but rather to clarify and relate them in such a way that they can be better seen and understood and handled by participants.

The burden of responsibility placed on the ethnographer is to acknowledge and make unavoidable the engagement with alternatives that is the grounds of moral and ethical action. The limit of ethnography is that it provides no assurance or certain means of resolving this prototypical conflict. The steps I have outlined merely establish the more favorable conditions for such an outcome. Yet they also teach that "good outcomes" may not occur. This tragic sense, mixed in with the optimism of a practicable approach, is the sort of mixed knowledge ethnography can at best produce. Of course, like any useful intervention, it too can have untoward effects; and this needs to be taken into account case by case. Yet the tragic sense of the ethnographer, along with her commitment to appreciate and sustain complexity in her analytic framing of the issues at hand, may help counterbalance both excessive American optimism about how problems can be fixed and excessive reductionism of the kind of data considered to be especially relevant to policy making.[29]

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ENDNOTES

[1]See Arthur Kleinman, *Writing at the Margin: Discourse Between Anthropology and Medicine* (Los Angeles and London: University of California Press, 1995), 41–67.

[2]For example, consider these recent contributions: Ronald Carson and Chester Burns, eds., *Philosophy of Medicine and Bioethics* (Dordrecht, Boston, and London: Kluwer, 1997); Raymond DeVries and Janardin Sabede, eds., *Bioethics and Society: Constructing the Ethical Enterprise* (Upper Saddle River, N.J.: Prentice Hall, 1998); Carl Elliott, *A Philosophical Disease: Bioethics, Culture and Identity* (New York and London: Routledge, 1999); Barry Hoffmaster, "Can Ethnography Save the Life of Medical Ethics?" *Social Science and Medicine* 35 (12) (1992): 1421–1432; Hilde Lindemann Nelson, ed., *Stories and their Limits: Narrative Approaches to Bioethics* (New York and London: Routledge, 1997); and Michelle Moody-Adams, *Fieldwork in Familiar Places: Morality, Culture and Philosophy* (Cambridge, Mass.: Harvard University Press, 1997). This last, strictly speaking, is not a work in bioethics, but a general contribution to moral theory. That is my point—the new bioethics overlaps with some of the most original approaches to moral theory in general.

[3]That this question has been present from the beginning of the contemporary bioethics movement in the 1960s can be seen in a paper by one of the early formative figures in the field: James Gustafson, "Context versus Principles," *Harvard Theological Review* 58 (1965): 191. That bioethicists still routinely are unable to provide useful answers can readily be seen in Ruth Macklin, *Against Relativism: Cultural Diversity and the Search for Ethical Universals in Medicine* (New York: Oxford University Press, 1999). Macklin, while acknowledging cultural diversity, treats it as the anthropologist's source of unacceptable relativism, and then clears the field by making the search for universal ethical principles the only serious and supportable moral procedure. This bit of sophistry—which stereotypes and stigmatizes contextual perspectives—simply declares the problem resolved by denying that there is one. This is not an encouraging sign that bioethicists coming out of an analytic philosophy background are making much progress on this core dilemma.

[4]These aspects of moral processes as social processes in local worlds are developed more fully in several of my recent publications. See Arthur Kleinman, "Everything that Really Matters: Social Suffering, Subjectivity, and the Remaking of Human Experience in a Disordering World," *Harvard Theological Review* 90 (3) (1997): 315–326; and Arthur Kleinman, "Experience and its Moral Modes: Culture, Human Conditions, and Disorder," in Grethe B. Peterson, ed., *The Tanner Lectures on Human Values,* vol. 20 (Salt Lake City: University of Utah Press, 1999), 355–420.

[5]For example, higher-order, abstract, ethical principles like beneficence and justice tell us almost nothing about the actual moral content of most patient-doctor interactions in American society, even ones among poor patients for whom there is an unjust social distribution of health and health-care resources that precedes people's access to the clinics. These principles are simply too remote from the local grounds of experience to be of much service in ac-

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tual cases, and yet at the level of the national regulatory system of policies and programs, they are obviously important.

[6]Philip Gourevitch, *We Wish to Inform You that Tomorrow We Will be Killed With Our Families: Stories from Rwanda* (New York: Farrar, Straus & Giroux, 1998), describes communities in Rwanda where all Hutus took part in the killing of their Tutsi neighbors and relatives; there was no internal criticism or resistance. Hence, here a translocal perspective is crucial.

[7]See Edvard Westermarck, *Ethical Relativity* (London: K. Paul Trench, Trabner and Co. Ltd., 1932); Kleinman, "Experience and its Moral Modes"; Tzvetan Todorov, *On Human Diversity in French Thought* (Cambridge, Mass.: Harvard University Press, 1993), 3, 24, 61; and C. A. J. Coady, *Testimony: A Philosophical Study* (Oxford: Clarendon Press, 1992). During the nineteenth century, the idea of human nature, which Foucault claimed received its modern form in the eighteenth century, got taken up in the wave of cultural representations of natural history. This lent to the idea of human nature its currently accepted biological significance, as in the nature and natural history of plants, animals, and diseases. See N. Jardine et al., eds., *Culture of Natural History* (Cambridge and New York: Cambridge University Press, 1996).

[8]The most immodest of claims for a biological basis of human nature and ethics is made by the influential sociobiologist E. O. Wilson in "The Biological Bases of Morality," *The Atlantic Monthly* 28 (4) (1998): 53–70. See also the account of E. O. Wilson in "From Ants to Ethics: A Biologist Dreams of Unity of Knowledge," *New York Times*, 12 May 1998, C1. Only vaporous dreams and romantic rhetoric can match the science that is cited to the claims about the biology of morality.

[9]See Kleinman, "Experience and its Moral Modes," and Arthur Kleinman, *The Illness Narratives* (New York: Basic Books, 1988), chap. 15.

[10]Hoffmaster, "Can Ethnography Save the Life of Medical Ethics?"

[11]Many methodologists have written about the postmodernist turn in ethnography, by its proponents and critics, in debating change. See, for example, James Clifford and George Marcus, *Writing Culture: The Poetics and Politics of Ethnography* (Berkeley: University of California Press, 1986); James Clifford, *The Predicament of Culture: Twentieth-Century Ethnography, Literature and Art* (Cambridge, Mass.: Harvard University Press, 1988); and George Marcus and Michael Fischer, *Anthropology as Cultural Critique: An Experimental Moment in the Human Sciences* (Chicago: University of Chicago Press, 1986). I am not certain, however, that this diverse literature of essays on ethnography does justice to what ethnography can achieve and how it makes its contribution. Even more recent collections that also illustrate important ties between theory and ethnography, although important theoretical statements, do not get at what I take to be most central in ethnography: namely, its engagement with experience. See, for example, Akhil Gupta and James Ferguson, eds., *Culture, Power, Place: Exploration in Critical Anthropology* (Durham, N.C.: Duke University Press, 1997). Rather critical readings into experience-near ethnographies themselves provide a sounder introduction to the field. In this regard, a few illustrative works, drawn from a potentially very large list, might include: Nancy Scheper-Hughes, *Death Without Weeping*

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(Berkeley: University of California Press, 1992); Anna Tsing, *In the Realm of the Diamond Queen* (Princeton, N.J.: Princeton University Press, 1993); Veena Das, *Critical Events: An Anthropological Perspective on Contemporary India* (Delhi: Oxford University Press, 1995); Michael Jackson, ed., *Things as They Are: New Directions in Phenomenological Anthropology* (Bloomington, Ind.: Indiana University Press, 1996); Mary Steedley, *Hanging Without A Rope: Narrative Experience in Colonial and Post Colonial Karoland* (Berkeley: University of California Press, 1993); Paul Farmer, *AIDS and Accusation* (Berkeley: University of California Press, 1992); Lawrence Cohen, *No Aging in India* (Berkeley: University of California Press, 1999); Phillipe Bourgois, *In Search of Respect: Selling Crack in El Barrio* (Cambridge: Cambridge University Press, 1995); Rayna Rapp, *Testing Women, Testing the Fetus: The Social Impact of Amniocentesis in America* (New York: Routledge, 1999); Tanya Luhrmann, *Of Two Minds: The Growing Disorder in American Psychiatry* (New York: Knopf, forthcoming); and Maya Todeschini, "Bittersweet Crossroads: Women of Hiroshima and Nagasaki," Ph.D. dissertation, Department of Anthropology, Harvard University, 1999. A new journal devoted to these issues is *Ethnography* (Sage Publications).

[12]Consider the writings of Barbara Koenig and Patricia Marshall, among others. For example, Patricia Marshall and Barbara Koenig, "Bioethics in Anthropology: Perspectives on Culture, Medicine and Morality," in C. F. Sargent and T. Johnson, eds., *Medical Anthropology* (Westport, Conn.: Praeger, 1996), 349–373; Barbara Koenig, "Organ Transplantation Reexamined?" *Medical Anthropology Quarterly* 9 (3) (1995): 393–397; and Patricia Marshall et al., "Ethical Issues in Immigrant Health Care and Clinical Research," in S. Love, ed., *Handbook on Immigrant Health* (New York: Plenum, 1998). Other works by anthropologist-ethnographers in bioethics include Linda Hunt, "Moral Reasoning and the Meaning of Cancer," *Medical Anthropology Quarterly* 12 (3) (1998): 298–318; Gelya Frank et al., "A Discourse of Relationships in Bioethics," *Medical Anthropology Quarterly* 12 (4) (1998): 403–423; Don Seeman, "One People, One Blood: Public Health, Political Violence and HIV in an Ethiopian-Israeli Setting," *Culture, Medicine and Psychiatry* 23 (2) (1999): 159–195; as well as the contributions by Lawrence Cohen, Veena Das, and Mary-Jo Good in this issue of *Dædalus*.

[13]See the experience-near ethnographic works listed in note 11.

[14]See Yunxiang Yan, *The Flow of Gifts* (Stanford: Stanford University Press, 1996).

[15]Of course, ethnographers will show that ethical formulations are ultimately also grounded in the categories and commitments of a local place, so that the claims to universality for bioethics need to be understood in a more modest sense of a quest and aspiration for translocal values.

[16]Nancy Scheper-Hughes, *Death Without Weeping: The Violence of Everyday Life in Brazil* (Berkeley: University of California Press, 1993).

[17]Das's ethnographic contribution to medical ethics is found in several of her works: "Moral Orientations to Suffering," in L. C. Chen, A. Kleinman, and N. C. Ware, eds., *Health and Social Change in International Perspective* (Cambridge, Mass.: Harvard University Press, 1994); "Language and Body:

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Transactions in the Construction of Pain," *Dædalus* 125 (1) (Winter 1996): 67–92; and *Critical Events: An Anthropological Perspective on Contemporary India* (Delhi: Oxford University Press, 1995).

[18]Das is presently editing a volume, *Rebuilding A World* (Berkeley: University of California Press, forthcoming), in which young ethnographers working in communities with extreme political violence come up against the same barriers. John Borneman, *Settling Accounts: Violence, Justice, and Accountability in Post–Socialist Europe* (Princeton, N.J.: Princeton University Press, 1997), examining serious wrongs perpetrated by socialist governments in East and Central Europe, argues for the crucial role of accountability for past abuses in legitimizing current democratic procedures in these countries. He holds up legal procedures of retributive justice as the way to undo moral injury. But Borneman does not deal with the way that such procedures have remade victims' suffering into a new object of professional appropriation that removes the moral heart of the matter, a subject about which Veena Das provides perhaps the most telling criticism. See Das, "Moral Orientations to Suffering." Martha Minow calls attention to the same problem in *Between Vengeance and Forgiveness: Facing History after Genocide and Mass Violence* (Boston: Beacon Press, 1998), where she makes the point that, after massive social violence, trials, truth commissions, and reparations all have their limitations. Both authors demonstrate that moral accountability and legal accountability are not the same thing, that acknowledgment of the significance of the former is not necessarily accomplished by the procedures pertinent to the latter, even though they may be all that can be accomplished in given cases.

[19]Paul Farmer, *Infections and Inequalities* (Berkeley: University of California Press, 1999).

[20]Salmaan Keshavjee, Sheri Weiser, and Arthur Kleinman, "AIDS and Hemophilia Testimonies: A Collective Experience of Illness and Suffering," unpublished manuscript.

[21]See Arthur Kleinman, *Writing at the Margin: Discourse between Anthropology and Medicine* (Berkeley: University of California Press, 1995).

[22]Rayna Rapp, *Testing Women: Testing the Fetus* (New York: Routledge, forthcoming).

[23]For studies undertaken from an anthropological perspective, see Ruth Behar, *Translated Woman: Crossing the Border with Esperanza's Story* (Boston: Beacon Press, 1993); and Kamala Visweswaran, *Fictions of Feminist Ethnography* (Minneapolis: University of Minnesota Press, 1994).

[24]Jing Bao Nie, "Voices Behind the Silence: Chinese Moral Views and Experiences of Abortion," Ph.D. dissertation, Institute of the Medical Humanities, University of Texas Graduate School of Biomedical Sciences at Galveston, 1998.

[25]Kleinman, *The Illness Narratives*, chap. 15.

[26]The next two paragraphs are drawn from Kleinman, "Experience and its Moral Modes."

[27]See, for example, Robert Desjarlais et al., eds., *World Mental Health: Policies and Priorities in Low-Income Countries* (New York: Oxford University

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Press, 1995); Farmer, *Infections and Inequalities*; and Veena Das, "Introduction," *Rebuilding a World.*

[28]This is modified from Arthur Kleinman, "Ethics and Experience," presented to the Workshops on Health Equity, Harvard Center for Population and Development, Harvard School of Public Health: Working Paper Series, No. 99.04, March 1999.

[29]In closing, I had hoped to review the relationship of moral processes and ethical deliberation to religion, which also can be understood as social process (i.e., ritual and ordinary devotional practices) and institutionalized discourse (i.e., theology), and which has in the past and can in the future play a clearly crucial role in bioethics. But this proved too much for a short paper to support and so will be the subject of another essay.

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However, none of these trends implies that what we have called *cultural* demedicalization will take place. The shifts in emphasis from illness to health, from therapeutic to preventive medicine, and from the dominance and autonomy of the doctor to patient's rights and greater control of the medical profession do not alter the fact that health, illness, and medicine are central preoccupations in the society which have diffuse symbolic as well as practical meaning. All signs suggest that they will maintain the social, ethical, and existential significance they have acquired, even though by the year 2000 some structural aspects of the way that medicine and care are organized and delivered may have changed. In fact, if the issues now being considered under the rubric of bioethics are predictive of what lies ahead, we can expect that in the future, health, illness, and medicine will acquire even greater importance as one of the primary symbolic media through which American society will grapple with fundamental questions of value and belief. What social mechanisms we will develop to come to terms with these "collective conscience" issues, and exactly what role physicians, health professionals, biologists, jurists, politicians, philosophers, theologians, social scientists, and the public at large will play in their resolution remains to be seen. But it is a distinctive characteristic of an advanced modern society like our own that scientific, technical, clinical, social, ethical, and religious concerns should be joined in this way.

Renée C. Fox

From "The Medicalization and Demedicalization of American Society"
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Veena Das

Public Good, Ethics, and Everyday Life: Beyond the Boundaries of Bioethics

IN RECENT YEARS MANY ANTHROPOLOGISTS have taken important steps to bring the moral, conceived as a dimension of all relationships forged in the context of the lived world of local communities, in conversation with bioethics, seen as the application of a set of codified norms to the practice of medicine.[1] It is widely acknowledged that bioethics as a discipline represents the evolution of secular norms for the conduct of relations between physicians and patients, especially in the context of critical moments when the patient must consent to submit his or her body to procedures that might in other contexts be seen as violations of bodily integrity. While much thought has been given to the refinement of concepts such as "informed consent," "disclosure," "truth-telling," or "patient autonomy" as providing the foundation of decision making in medical interventions and in the conduct of clinical trials, the imagined context of the exercise of these concepts is largely Western. In fact, it is in the context of the legal and juridical framework provided by both legislation and case law that the anchoring concepts of the reasonable person, best interest, and therapeutic interest have been developed in specific national contexts.[2]

It is important to note that while the consolidation of these concerns is traced to the decade of the 1960s in the United States with the professionalization of bioethicists as a commu-

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nity,[3] questions of consent go back to the nineteenth century not only with regard to compulsory vaccination acts in the United Kingdom and in Europe but also with regard to the testing of the first laboratory-produced prophylactic vaccine against cholera, by Haffkine, of which field trials were held in India in 1891. The latter case generated considerable debate on who could consent (e.g., could prisoners be said to have given their consent freely?), on whether the authority of the state should be evoked in generating consent for experimental procedures, and on the difference between subjects and citizens. Admittedly, these questions were grounded in different kinds of legal and political realities from those that move the discipline of bioethics today. But as attention shifts to questions of ethics in non-Western countries and we search for other over-arching concepts, we should keep this genealogy in mind. Within the community of bioethicists today, the purpose of the turn toward non-Western countries is to find alternative anchoring concepts to those of patient autonomy—concepts such as bioethics as a special case of love for life, or harmony and interrelatedness, which many feel may carry a better resonance with Asian cultures.[4] Innovative attempts are also being made to understand the trials and tribulations of healers in these countries by documenting and analyzing the actual decisions that clinicians have to make regarding resource allocation, disclosure, and the necessity of triage.[5] It seems clear that unless we can come to grips with the everyday life within which moral and ethical questions may be grounded for clinicians, patients, and policymakers, there is little use in debating the relevance of bioethics for low-income countries. I hope to address this issue by taking two scenarios in which questions of health and disease are embedded. These scenarios have evolved in the context of globalization and its impact on policy-making in low-income countries and address larger questions of medical ethics. Let me first give a brief account of the pressures generated by globalization to move toward a new way of conceptualizing health as a global public good, recognizing its implications for the understanding of disease experience in low-income countries such as India.

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I argue that the focus of bioethics in low-income countries, when it has grudgingly tried to take that context into account, has been either on high-order ethical systems or on the extension and applicability of concepts such as patient autonomy.[6] In contrast, reconfiguring the notion of health as a public good (both global and national) has the merit of focusing on questions of equity and justice, but, even more, it allows us to bring to the fore ethical issues in public health such as the management of epidemics or the conduct of mass immunization programs. The assumption of a global or national consensus in the face of an immediate or future threat of disease (especially communicable diseases) often eclipses issues pertaining to the manner of implementation of preventive programs, ignoring questions of individual versus social risks. What is fascinating in this context, though, is that an implicit division between the diseases of the affluent and the diseases of the poor comes to be instituted in both discourse and practice. As an example, we can consider the gamut of legal and ethical questions that have been debated in the case of the AIDS epidemic, including issues of consent, disclosure, resource allocation, and the rights of patients over new experimental medicines as a resource.[7] In contrast, there is a relative silence on ethical issues in relation to other communicable-disease management, such as the smallpox eradication program or the universal program of immunization against childhood diseases. We know that issues pertaining to vaccination against smallpox, cholera, and plague were historically closely tied with questions of political rights, civil disobedience, rights of subjects versus citizens, and the nature of consent.[8] Today, however, it is assumed that all these issues were settled in the nineteenth century as far as the "old" diseases are concerned. However, a close look at the manner in which visions of public health are implemented today raises *new* issues: these are not simply repetitions of old concerns but rather bear the signature of the contemporary context of globalization and the new anxieties about the spread and management of disease with increased global flows of people, pathogens, and technologies.

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HEALTH AS A GLOBAL PUBLIC GOOD

International cooperation in the control of infectious diseases such as smallpox, plague, and cholera is already more than a century old.[9] Since the global spread of the human immunodeficiency virus that began in the early 1980s, it is recognized that many of the new bacterial or viral pathogens are capable of global spread.[10] Further, new infectious diseases or resistant strains of old pathogens have made it obvious to many that these threats not only affect local populations but also constitute a serious danger to international health.[11] In addition, the inappropriate use of antibiotics in many parts of the world among both human and animal populations is likely to have contributed to the emergence of resistant strains of pathogens, causing such diseases as tuberculosis, cholera, and typhoid to take more virulent forms.[12] Thus, there is not much scope for disagreement that control of infectious diseases, including mechanisms for disease surveillance, should be treated as a global public good defined by the criteria of "nondivisibility" and "nonexcludability."[13] But is there even more at stake?

Traditionally, the division between what is private and what is public in disease was considered clear-cut: because of the operation of externalities, the control of communicable diseases was regarded as a public good. However, since noncommunicable diseases were seen as lifestyle diseases, it was assumed that the burden for these should be borne by individuals whose private choices with regard to diet or exercise increased the risk and severity of these diseases. Lincoln Chen, Tim Evans, and Richard Cash have questioned this assumption and argued that globalization is blurring the distinction between what is public and what is private in health.[14] For instance, while tobacco or drug consumption is regarded as a matter of private decisions, the use of advertising, the manipulation of international networks, and the dumping of pharmaceuticals in low-income countries create conditions for their consumption as a direct consequence of globalization. Hence, diseases resulting from such abuses cannot be regarded as being only of private concern.

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The processes of globalization raise problems of equity in health care not only in ensuring equal access but also in making it necessary to prioritize which diseases will receive resources from international organizations and national programs. The global consensus on the eradication or elimination of certain diseases, such as smallpox or polio, that represent global threats may well have been reached at the cost of other diseases that are of greater local importance.[15] Though technical feasibility may have led certain diseases to be prioritized for international attention, such dividing practices in global programming are not conducive to equity in health-delivery systems. As Chen and his colleagues state:

> A recurring issue in building international cooperation for surveillance is the comparative importance of various threats to different population groups. The public in rich countries fears the importation of a devastating new virus, while ordinary people in poor countries suffer from common infections such as diarrhea and respiratory diseases. These different health concerns present divergent surveillance priorities, generated by the ready access of rich populations to effective vaccines and antibiotics that are financially or logistically inaccessible to many poor populations. Similarly, a global goods perspective does not by itself resolve the dilemma of which disease should receive priority in global surveillance or how limited global resources should be prioritized.[16]

I believe that these observations raise some important ethical concerns: they lead us not only to such questions as resource allocation and equity in heath care but also to the conflicts between what Arthur Kleinman has called the "moral" as a dimension of the local, and the "ethical" as the application of abstract principles to the definition of the good.[17] I propose to engage these issues ethnographically, drawing from work that I have conducted in collaboration with a team of researchers.[18] How does global programming work in the eradication and control of disease when seen from the national and local perspectives of countries in which it is implemented? Does it raise issues other than those of resource allocation that may be relevant for defining our moral or ethical stance toward these programs? What about diseases that are not targeted for eradi-

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cation or control? How do we address such suffering that is seen in global policies to be a result of purely private decisions? Is this a defensible way of classifying diseases? Let us move to a discussion of the empirical context of these questions.

IMMUNIZATION AS A GLOBAL PUBLIC GOOD

The eradication of smallpox from the world in 1976 is widely regarded as an example of a global public good. If questions of national sovereignty, informed consent, and citizen rights were implicated in the method and manner in which the campaign was organized, they were elided under the euphoria of having achieved success in the eradication of this dreaded disease.[19] The international health organizations involved in this project have also learned much from their experience. Instead of relying on the police powers of the state to achieve high coverage in mass immunization programs (which was the method in the campaign for the eradication of smallpox), these organizations now increasingly rely on techniques of social marketing to achieve universal coverage against polio and other childhood diseases. Thus, immunization may be seen as a relatively simple and uncomplicated example of a public good that meets the criteria of "nondivisibility" and "nonexcludability." It is for this reason that it also presents an interesting case of the ethical issues in routine practices of public-health management authorized by international organizations.

Although child-immunization programs were included in policies on public health in independent India, universal immunization programs were initiated only in the mid-1980s. The formidable problems in delivery of vaccines and especially in cold-chain management (refrigeration for vaccines) were not conducive to a program of mass immunization in the decades immediately following independence. In any case, vaccination was seen more as a technique for the control of epidemics than as a routine practice for protection against common childhood diseases. It was only in 1985 that the Expanded Program on Immunization, followed by the Universal Program on Immunization (UPI), was adopted in India, both because of the push given in this direction by the United Nations Children's Fund

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(UNICEF) and simultaneously by the establishment of the Immunization Mission during the tenure of Rajiv Gandhi as prime minister in 1985. The adoption of the UPI can be interpreted as a part of the process of globalization in communication and commerce. It signaled a greater concern with child health on the part of international bodies like UNICEF and the World Health Organization (WHO). It also constituted a strategic shift in methods of resource mobilization for international organizations, since high coverage achieved under immunization programs could be presented as a tangible success story and could convince international donors that money was being effectively utilized. In the face of this success, are there ethical concerns that need to be addressed?

UNICEF and WHO have repeatedly made the claim that the target of immunizing 80 percent of the children of the world has been achieved under its Universal Program on Immunization. The major task now, they contend, is to cover the remaining 20 percent of children. As an example of this rhetoric of success, I offer the following two statements made by international experts:

> We have moved immunization programs in developing countries from 20% to 80% in one decade. . . . Despite problems arising from lack of refrigeration for vaccines ("the cold chain"), sterilization and the small number of educated health workers in the target countries, the universal childhood immunization programs have been hugely successful . . . communities have been mobilized using a variety of strategies, from withholding birth certificates (and thus denying any government child subsides) until the child is immunized to massive poster campaigns.[20]

The second statement, fairly typical of the celebratory rhetoric, is found in the 1998 UNICEF *Progress of Nations Report*:

> Immunization is the greatest public health success story in history. Between 1980 and 1990, a massive effort raised coverage rates worldwide from 5 percent to 80 percent.[21]

Despite some reservations about the quality of the data, most public-health officials now assume that there has been a significant reduction in child mortality, attributable to the success of

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immunization programs. Whatever the exact contribution of immunization programs to the reduction of childhood mortality,[22] there is little doubt that the caseload for vaccine-preventable diseases has decreased considerably. Thus, the question is not one of doubting the importance or the success of childhood immunization programs for low-income countries. Yet ethical issues may be posed not only in the case of global programs that have *failed* (such as the program for global eradication of malaria, or the disastrous experience of mass immunization against yellow fever in Brazil),[23] but also for those programs that have *succeeded*, such as the eradication of smallpox and the Universal Program on Immunization.

MACRO PICTURES AND MICRO REALITIES

Although vaccines against childhood diseases are available through the private sector in India, the major costs of immunization as well as the organization of delivery is in the hands of the government. The logistics of organizing mass immunization, including cold-chain management, in a country as large and diverse as India are indeed staggering. From the first step, the production of vaccines, to the final step when the antigen reaches the body of the child, logistics of production, distribution, and consumption of vaccines must be coordinated. Though many social scientists have been critical of the way that immunization programs have been implemented in local communities—disparaging the metaphors of military campaigns used in these programs,[24] or emphasizing risks of particular vaccines[25]—there is little doubt that the macro picture on childhood immunization in India shows that the overall coverage has improved dramatically. Still, the results have not been uniform across the different states in India in all years. States with greater resources, higher growth in income, and better governance have generally performed better. The aggregate picture of high coverage masks the reality of wide gaps in the performance of different states in the immunization program. This raises important issues about the ethics and politics of representation in international forums. How are these numbers of coverage generated in the first place?

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The enormity of the task at the level of global and national programming for immunization programs to function should not make us overlook the details of how protocols for arriving at targets are devised for each micro region as well as the protocols for reporting on the coverage achieved. The role of numbers in the generation of trust in biomedical research has been noted in recent research.[26] Our question is how is this trust, in the case of mass immunization programs, generated and sustained?[27] In the process of generating this trust, are there other kinds of information that are not allowed to surface, and does this have any implication for both public and private decisions regarding immunization? What are the ethical obligations of reporting and disclosure when the actors are not clinicians making decisions with regard to individual patients but large social actors, such as international organizations and state bureaucracies?

In order to address these and similar questions, Ranendra Das and Purnamita Dasgupta have collated data from existing governmental and nongovernmental reports on immunization coverage for the major Indian states.[28] They have estimated and projected the net infant and child population from independent sources in order to review claims made by international organizations and ministries of health about their success in achieving the targets for immunization. It is obvious that targets for immunization can only be fixed realistically on the basis of data on the number of children in the population being served. But given the limited reach of compulsory registration of births, the information on children born between the census years, avaliable only through the sample registration system, is scanty. Given these difficulties, at present the targets are set by translating the birth rate of a state over a period of time into estimates of the net number of infants to be covered. Note, however, that the birth rate of a state is computed on the basis of data collected during the census years—assumed to be valid during the years in between as well—and is then handed down to each Primary Health Center (PHC) as the target to be achieved. These targets are obviously subject to some error due to fluctuations in intra-year births and the local variations in contraceptive use. Further, the coverage figures of immuniza-

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tion, as for other target-driven programs, tend to be upwardly biased by the hierarchical nature of record keeping in which targets and goals move from top to bottom while information moves from bottom to top. Thus, while the targets for the number of antigens to be distributed are given by state ministers of health, the opposite flow of information on antigens distributed in the area covered by the PHC, as well as the occurrence of vaccine-preventable diseases, moves upward from the PHC to the higher levels such as the District Health Center and the Ministries of Health at the state and central levels. Further, the incentive structure in these programs rewards local officials for achieving high coverage but punishes them for reporting on the difficulties of achieving the set targets. Therefore, the quantitative estimates are subject to inestimable error margins. Nevertheless, reduction in the disease burden from vaccine-preventable diseases over time suggests that the picture of high coverage is correct, *but only in broad qualitative terms*. Using descriptive statistical models to compare the performance of immunization in different states of India, Das and Dasgupta concluded that although aggregate figures of immunization coverage showed more than 85 percent achievement of targets, *there were significant variations in the performance of different states*.[29] In general, the poorly governed states, namely, Uttar Pradesh, Rajasthan, Madhya Pradesh, Bihar, and Orissa, which score poorly on all indexes of physical quality of life or on the human development index, also show gaps in immunization coverage. By carrying out demographic projections for estimating target population for immunization in the year 2006, the researchers predicted that despite a decline in the birth rate, the *total number of children would steadily go up in all the states*. This means that in the underachieving states mentioned above, the number of children without access to immunization is likely to increase, rather than decrease, if the present trends continue. This is because, in addition to new cohorts of children, there would be an increasing population of children in the older cohorts who would not have been vaccinated, seriously jeopardizing any herd immunity in the population. *Given this scenario, it is likely that local-level epidemics of vaccine-preventable diseases will continue to occur in these under-achiev-*

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ing states. In the global scenario of health, the reemergence of local epidemics of vaccine-preventable diseases such as pertussis and diphtheria in Russia and parts of Latin America is already cause for concern. That such epidemics are likely to occur even in areas where 80 percent of the children are supposed to have been fully immunized further threatens international health and, more importantly, also has serious consequences for the administration of health in national and local communities. In order to understand the latter we need to see the two sides of surveillance: one as a global public good, as argued by Zacher,[30] and the second as a process of producing political documents at the level of international organizations—national programs as well as local administrative practices.[31]

RECORDS AS POLITICAL DOCUMENTS

As mentioned earlier, the emphasis on disease eradication and universal coverage of children was part of a new strategy of resource mobilization within international organizations. I suggest that this has influenced the structure of record keeping, the narrative thrust being toward the production of a success story. This becomes clear, in the first instance, because records are structured so as to count *the number of doses of various antigens distributed and not the number of children immunized.* That is to say, coverage in different countries is calculated on the basis of the distribution of doses in relation to the estimated number of children in the population to be covered. It has been assumed in most international and national reports that these figures are interchangeable—i.e., if x number of doses of antigens have been administered within a district, then x number of children have been immunized in that district. Hence, claims have been made, as noted earlier, by both UNICEF and WHO in several reports that 80 percent of the world's children have been immunized and that the task now is to reach the remaining 20 percent. This is seriously misleading in the case of India and perhaps other countries as well. On the basis of an analysis of the primary data collected by the National Family Health Survey (NFHS), as well as the micro studies conducted under the project on *Social Science and Immunization*, it was found that

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the *number of partially immunized children* (i.e., matching the age of the child with the number of doses he or she had received) was significantly high in the population.[32] More than that, these studies found that districts in Gujarat and Kerala reporting high levels of coverage contained a significant number of partially immunized children. A pool of nonimmunized or partially immunized children continues to exist; they are easy prey to local epidemics of vaccine-preventable diseases. Hence, we have to conclude that though the overall incidence of these diseases has come down, there are likely to be local incidences of epidemics for years to come. Why have these facts received only selective attention in the international documents? While attention has been drawn to the fact that the data on coverage may be unreliable, because of the local-level administrative practices,[33] it has hardly ever been acknowledged that the protocols of record keeping and reporting formulated at the level of international organizations are themselves conducive to obscuring the large number of partially immunized children in the population. It is part of the politics of numbers that only certain kinds of information are provided in discussions of the success of immunization programs. Yet it is clear that the protocols of reporting immunization coverage need to be changed in the direction of child-centered records and that the story of the success of immunization programs will be significantly modified when such records begin to be available.

I do not mean to suggest that there are no serious problems in the management of records at local levels. There, the system of disease surveillance is at present seriously deficient. Despite claims to the contrary, local health workers are inadequately trained to recognize vaccine-preventable diseases. At the level of District Health Centers, records of the occurrence of vaccine-preventable diseases either are not maintained or prove to be haphazard. With the exception of polio, on which surveillance has been increased since it is targeted for eradication by the year 2000, there is no awareness among health workers, even in the states with better primary health facilities such as Kerala and Gujarat, that it is important to maintain records of the incidence of vaccine-preventable diseases. Given this scenario, it is difficult to monitor and measure the exact impact of

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immunization programs on the reduction of disease. Thus, one may say that childhood immunization programs have led to a significant reduction in child mortality only if one takes this statement to be true in a broad qualitative sense. It is difficult to measure the exact contribution of immunization programs to the reduction of child mortality in the absence of reliable data on the actual prevalence of vaccine-preventable diseases and their contribution to cause of death for children under five years of age.[34]

Despite the tone of triumphant victory in many of the public campaigns of WHO and UNICEF, troubling incidences of local-level epidemics continue to surface. It was confirmed by WHO on April 9, 1999, that the cause of an outbreak of paralysis among children living in Angola, Central Africa, was polio. A WHO mission team, dispatched to work with the Ministry of Health to control the outbreak, discovered that in almost all cases the children were under five, and most were aged between one and two. They were found to be living in overcrowded municipalities in the capital, Luanda. WHO also received confirmation from the nearest testing center, the National Institute for Virology in South Africa, that wild poliovirus type 3 had been isolated from eleven of the twenty-two stool samples taken from paralyzed children in Angola. Ninety percent of the paralyzed children were either unvaccinated or partially vaccinated, and therefore unprotected from the virus. Given the conditions of terror under which children have been living in Angola because of the devastating violence in the country, this is not unexpected. In fact, UNICEF's program on children under threat is an important resource for families and children living in such conditions. But what gives salience in the work of international organizations to this report on the breakout of polio is the concern with the implications of such local-level epidemics: they may seriously jeopardize the global program of polio eradication by the year 2000. Yet what would appear to be much more devastating for the local societies is the totality of conditions under which children in such war-torn areas are compelled to live. But to return to less grievous circumstances, cases of outbreaks of local epidemics continue to surface in different parts of India: it seems clear that claims of 80 percent

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of children having been vaccinated are exaggerated, at least if the incidence of children who are only partially immunized is taken into account. Does this story of numbers and related narratives have any consequences for the redefinition of bioethics?

The first issue, that of accountability, is an important ethical principle in democratic societies. When local-level epidemics occur in areas that have reported high coverage, blame is attached either to the local health workers or to the communities where the epidemic has occurred. In several cases, punitive action has been taken against local-level health workers, such as the Auxiliary Nurse Midwife, on the assumption that they had fudged the figures. Yet it is also possible to think that pressures generated by the zeal to forge a success story on the part of international organizations has led to a situation in which ill-trained local health workers have been compelled to implement programs for which logistic support is poor. It is not those who design these programs who have to take responsibility for such failures but the local-level health workers against whom punitive actions are commonly taken when local epidemics come to light.

The second significant aspect of record keeping is that until recently, local-level health workers were not encouraged to report adverse reactions to vaccines, despite evidence of some definable risk from the component of whole-cell pertussis vaccine in the DPT vaccine. Many functionaries in the international health organizations and in the national health bureaucracies argued that any emphasis on adverse reactions could cause panic, leading to resistance on the part of users to vaccines. This has meant that important inequalities have been introduced in the system of health administration. Parents whose children suffer from adverse reactions to vaccines have various legal rights to compensation in many affluent countries. Both the United States and Australia have no-fault immunization injury compensation acts, designed to protect the nation's vaccine supply from crippling lawsuits.[35] In low-income countries, in contrast, it is difficult to know the impact of adverse reactions because they are not recorded: the protocols for record keeping devised by national ministries of health under supervi-

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sion from WHO and UNICEF did not include, until recently, provisions for reporting adverse reactions. My argument is not that there is a simple way of balancing risks from disease and from adverse reactions for the population as distinct from the individual; these are indeed complicated exercises. Nevertheless, the taboo on the discussion of adverse reactions in a context in which immunization coverage is said to have moved from 5 to 80 percent coverage is stunning.

We come back to the function of numbers in the generation of trust in biomedical research. Our studies on immunization show that the structure of records may itself be a function of control over information that can suppress claims over certain kinds of goods. The success stories on immunization coverage hide troubling questions about how claims over citizenship can be held hostage to officially sanctioned programs. Consider the statement made by Dr. Hill quoted earlier, in which he claimed credit for the strategy of denying birth certificates and thus related government subsidies to babies who had not been immunized, and presented it *as a successful strategy for enhancing coverage*.[36] To my mind this signals an arrogance on the part of international organizations that can deny rights to citizens in the pursuit of aims and targets that are no doubt important but do pit, perhaps not a right against a wrong, but certainly one right against another right. Not only that, but it is entirely possible that the nonimmunized children come from families that are most vulnerable to economic and political exigencies in the first instance and are fighting for survival—families who do not have the resources, such as a mother's time, to access even free government facilities. To further penalize such families by withholding subsidies to which they are entitled as citizens seems like an extra-constitutional exercise of power. I would like to offer here an example of the kind of local context in which the zeal for a government program such as immunization may be met with relative apathy in comparison to the other needs to ensure the survival of a child.

Let me say clearly that what I describe is not a typical situation. It is an extreme situation, but one that asks for some meditation on the immense gap between utopian principles and desperate local realities. International organizations have, no

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doubt, designed immunization programs for the good of children. But should those who are unable to take advantage of these programs be *punished* by, say, the denial of other government subsidies in order to achieve these public goods? The ethnographic account is taken from field work I conducted in villages in the Sarguja District in the Bilaspur Division in Madhya Pradesh in 1997—an area that is marked by a rain-fed single-crop economy and a chronic food shortage.[37] It describes one encounter in the field.

> We had visited Tutpara, the hamlet in which the school was located in a village in Sarguja, where prominent persons of the village had gathered to greet me. We then walked to a tiny hamlet of ten related households of the Pahadi Korvas, higher up on the hills, where we were greeted by a tall man, obviously in an inebriated condition. A number of women (five or six) were sitting in a row outside one of the makeshift shelters. At a distance under a tamarind tree sat a young mother (the intoxicated man's daughter) with a small baby in her lap who was sucking at her breasts.
>
> The tall man pointed to the young woman suckling her baby and said, "Look, look there—that baby is burning with fever. I walked all the way yesterday to a nearby town to get a pill. I spent whatever money I had earned in the town yesterday and trudged back late at night but the pill has made no difference." I touched the baby's forehead—it was burning and he was sucking at the breast desperately but the mother did not seem to have much milk. I asked the mother if she had eaten anything. Now the others joined in the conversation and said that they were waiting for some of the men to return. There was no food in any house. They would cook something if the men managed to earn some rice or some coarse grain. Concerned about the baby's condition, I asked if they knew about oral rehydration solution (*jevanghol* in local parlance). They did not know anything about it—the ANM (Auxiliary Nurse Midwife) never came up to the hamlet. However, on National Immunization Day last year they had all been taken to the school in the main hamlet and the babies were administered the oral polio vaccine drops.
>
> The Sarpanch (headman), who was accompanying me, was getting quite defensive.[38] He said if these people do not come down, if they do not tell us what troubles them, how can we help them? I asked

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the Sarpanch to explain to the young mother and the older woman sitting next to her how important it was for the baby to receive fluids. In his dialect, he began to explain. "You have some salt in the house, don't you? Well take this much sugar, put it in this much water and boil it and then put a pinch of salt in it and squeeze a few drops of lemon. No sugar in the house? Yes, but go down to someone in the lower hamlet—they may not give you sugar if it is for yourself, but if you say that it is needed to save the life of the child they will surely give you a fistful." The women nodded. "Where will you get the water from?" I asked. Now a new problem arose, for the nearest pump was not working. They were all drinking water from a stream nearby that was stagnant and dirty. The Sarpanch told the baby's grandfather that the water must be boiled and cooled. I was beginning to see the hopelessness of the situation. No sugar, no source of clean drinking water, and a shortage of fuel. But the man who was inebriated again got aggressive. "Whatever you say, we will not go to anyone's door to beg." The women were listening more intently and I thought they intended to follow it up. "But do not just feed it to him all at once," I said, "give it in small sips." (How shall I demonstrate that?) The woman took a leaf, folded it in a kind of spoon and said "like this?" The Sarpanch promised to help by getting a packet of oral rehydration solution.

The case of the childhood immunization program that I have chosen to discuss raises some exceptionally difficult ethical questions precisely because it is a public-health success story. I have suggested that what allows private aspects of health (such as questions of individual consent and the balancing of individual risks versus risks to a population) to be obscured is the emphasis on immunization as a global public good to the exclusion of immunization as a resource equally for local communities and for individual children. While one can state with confidence, on the basis of current studies on coverage and sustainability in India, that the returns on investment in immunization programs in public health are large,[39] it is equally clear that an attention to the kinds of ethical issues that I have discussed would lead us to reconfigure immunization as both a public good and a resource for securing better health for individuals. Thus, individual risks, like those involved in administering whole-cell pertussis vaccine, have to be weighed against

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the cost effectiveness of the use of this vaccine for a population. But such changes in attitude are not likely to occur if local-level health workers are increasingly socialized into the practice of health care as implementers of international or governmental programs rather than as those responsible for the health needs of local communities. The case of the baby from Tutpara who was at risk of dying from dehydration suggests that Auxiliary Nurse Midwives may feel that they have fulfilled their duties if they have administered vaccines to children, and they may become blind to the urgent survival needs of the children in the communities that they are supposed to serve. Byron Good's work on how pedagogic practices in medical institutions produce a particular kind of medical subject needs to be supplemented by similar studies in the training of local-level health workers and the production of subjectivity in which they come to understand their functions only within a hierarchy of workers who are charged with *implementing* government programs.[40] It also creates a dichotomy between medical practices in the governmental sector and those in the private sector of health care, for patients are compelled to seek curative care in the private (often informal) sector, which flourishes in an unregulated manner. Taking a critical look at the division between public and private, therefore, has special salience for questions of medical ethics, which are difficult to address within the present boundaries of bioethics.

GLOBAL PUBLIC GOODS AND PRIVATE GOODS REVISITED

The practice of biomedicine, in both the formal and the informal sector in low-income countries, has been the subject of many important anthropological studies.[41] It is clear from these studies that there is a sprawling private sector in health care, regularly used by the poor, who spend disproportionate amounts of their income on drugs, injections, and I.V. drips. Much of this expenditure is incurred on products that are either inappropriate or actually harmful to the health of those who consume them. At the policy level, much of the discussion on drug policy continues to be dominated by the essential drugs concept formulated by WHO during the twenty-eighth World Assembly

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convened in 1975. On the ethical issues involved in the widespread use of inappropriate drugs, neither bioethics nor indeed the anthropological profession has systematically formulated any principles on which discussion could be based. It is in an attempt to open up the question of the practice of biomedicine outside the privileged contexts of Western countries that I present the following issues.

One key recommendation of WHO in 1975 was the promotion of the essential drugs concept under which priority was accorded the task of assuring accessibility to necessary drugs for basic health needs. The national drug policy in India, as in many other low-income countries, is based on the essential drugs concept.[42] Yet availability of drugs does not mean that they are used in a manner considered appropriate according to expert norms of biomedicine. Many anthropological works have demonstrated that the meaning of medicines at local levels derives from the way in which they tend to be embedded into different cosmologies, concepts of the body, and notions of interrelatedness.[43] Anthropologists are generally uncomfortable with the notion of "irrational" or "inappropriate" drug use. As Etkin and Tan summarized this genre of research: "Rather than documenting 'irrational' use, the authors reveal the reasoned basis that underlies people's use of medicines."[44]

We are confronted here with the well-known problem of different rationalities. Yet it seems to me that the question of expert knowledge versus lay understanding cannot be dismissed quite so easily. Formulating their famous criticism of the "exotic bias" in anthropological research, van der Geest and Whyte put it as "overlooking the use of aspirin for head-ache while noticing the use of elephant dung for dizziness."[45] This example draws attention away from the fact that often it is not "aspirin for headache" but "tetracycline for colds" or "valium for weakness" that creates cause for concern. The discomfort of anthropologists with such terms as "irrational," regarding the use of drugs, arises because such terms create a "geography of blame."[46] Perhaps the problem lies in the manner in which "people's rationalities" are seen as autonomous from the practices of health care, including biomedical care, in which their lives are

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increasingly embedded. Let us consider some of the consequences of this simple proposition.

The private spending on health in India accounts for 78 percent of overall health expenditure and 4.7 percent of GDP. It is clear that the poor are spending a large amount of their incomes on curative care, yet the quality of their care is hardly ever discussed in the literature. This is not to say that powerful critiques of biomedical practices, especially in relation to conditions of poverty, have not been made,[47] but rather that the matching of expenditure with the services and products received in the everyday life of poor communities has not been the subject of systematic investigation. There are clear indications that in a market-driven medical system with poor regulation, the poor are not getting appropriate services for what they are paying. On the basis of data on health expenditure from *The Survey of Living Conditions* carried out by the World Bank in 1996 on 2,500 households from 125 villages of Bihar and Eastern Uttar Pradesh, Jishnu Das and Saumya Das compared the distribution of expenditure incurred by these households to the distribution that would obtain from an optimal drug regimen using U.S. standards and the Monthly Index of Medical Specialties, a publication that details the maximum prices for drugs available in India.[48] They found that in the case of the two largest reported illness categories, namely, fever and diarrhea, with a reported recovery period of less than two weeks, the difference was in the order of 400 percent. In other words, the villagers were being overmedicated or were being charged far above the market prices for the goods and services they were receiving.

Other indirect evidence supports this conclusion. In a recent study based on the cluster-survey method conducted in the Chittagong metropolitan area, where 360 mothers were interviewed on incidences of diarrhea and dysentery in their children, Alam and Rehman found that in 73.5 percent of the cases of acute diarrhea and 21 percent of the cases of dysentery, inappropriate drugs (metronidazole and other antibiotics) were prescribed.[49] What is more, those who consulted qualified health professionals were at 5.7 times higher risk than others of receiving inappropriate drugs.[50]

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Other studies indicate the pervasive use of drugs and injections.[51] While there is concern on the misuse of injections due to the risk of HIV infection, the persistent and inappropriate use of antibiotics and steroids also has other adverse consequences. Such use may contribute to the emergence of new infectious diseases as well as resistant strains of old infectious diseases. Resistance to antimicrobial agents has been recorded since 1940, when penicillin-resistant Escirichai coli (E coli) was documented. Even before the global use of penicillin, resistance had already been detected in both gram-positive and gram-negative organisms. Many suspect that we have already entered a post-antibiotic era. The 1990s heralded the era of multidrug resistance, with reports of multiple-drug-resistant Mycrobacterium tuberculosis, penicillin-resistant Streptococcus pneumonia, fluconzole-resistant Candida, and methicillin-resistant S.aureus with reduced susceptibility to Vancomycin. Given the dramatic increase in the incidence of multiple-drug-resistant organisms and the mounting evidence of resistance transfer from one organism to another, we may well witness a combined growth of nosocomial pathogens for which there may be no antibiotic solutions.[52] The poor, who are being given cheaper antibiotic drugs, are likely to be already facing such a disease scenario.[53]

But if bioethics has failed to address these questions, unfortunately anthropology has not done much better: it has evaded ethical issues that arise when one comes face to face with local practices that may endanger the health, or even the lives, of those practicing them. Sympathy for such concepts as the rationality of particular belief systems and cultural efficacy, as well as an awareness of how the alliance between state and biomedical power has often been used to stigmatize the poor, has led to an anthropological stance that is deeply ambivalent in facing the consequences of such health-seeking practices.

A fairly conservative but typical view of the object and method of medical anthropology (or the anthropology of medicine as French anthropologists prefer to designate it) is presented by Marc Augé:

> . . . ethnomedicine involves apprehending the conceptions that certain societies have of illness, remedy, healing, and health. From a

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> study of this particular object, ethnomedicine can proceed to consider the objective quality and effectiveness of the procedures and products used by these societies, or it can relate their conceptions of illness and health to other aspects of their cosmology or global anthropology, so as to understand from within, as it were, how relations to the other, relations to the world, and power relations function in those societies.[54]

There are many exceptions to the picture presented by Augé. Anthropologists have engaged with some of the most controversial contemporary issues, such as the emergence of new infectious diseases,[55] organ transplants,[56] new reproductive technologies,[57] and the human genome project.[58] Yet there is no denying that the attitude toward "people's beliefs" regarding illness, efficacy of treatment, and other such issues often follows the interpretative stance gestured by Augé.[59] Can we treat "certain societies" and their conceptions of illness and health as if they stand independent of the global processes of advertisements, of social marketing of medicines, and of the organization of health care, however deep our attachment as anthropologists to the sanctity of the local or the "native" point of view?[60] With the increase in global flows and the increasing availability of new and more expensive drugs, anthropologists will be obliged to engage with such problems that have the potential of changing the ecology of microbial resistance and creating new diseases of the poor that may be even more difficult to treat in the future. They cannot simply point an accusing finger at bioethics while maintaining a studied innocence on these questions.

THE LOW BP SYNDROME

Let me give some examples from a study of the burden of disease and health seeking among the urban poor in Delhi, in which my colleagues and I are currently engaged.[61] We use the method of detailed illness histories that are collected from each household and followed by a weekly morbidity survey, which is in the fourth round at the present time.

Before we commenced the weekly morbidity survey among the households under study, I conducted detailed interviews on

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the history of past illnesses of each member of the household. I was struck by the frequency with which low blood pressure ("low BP") was identified as a major category of disease, especially by women. Here is a typical case presentation.

> Pushpa (name changed) is somewhere between twenty-five and twenty-eight years of age. She has two daughters. The younger daughter suffers from multiple congenital disabilities. Pushpa is pregnant and hopes very much to have a son "who will light the name of the lineage." Her husband is a vegetable vendor. She makes some money by cutting and stitching for the local market. Pushpa complains that for many years she has suffered from "low BP." She can reel out numbers—90/60, she says. Her symptoms are persistent body ache, blinding headaches, weakness, and sadness. She says that she has no life in her hands and feet, the world appears to bite her, she feels like running away—all of which she is convinced is because of her low BP. When she was pregnant with her second child, she went out to dry clothes on an electric line and received an electric shock of high intensity. She attributes the multiple congenital disabilities of her daughter to the fact that she received a shock when in the womb. She took her daughter to local practitioners and then to the Kalavati Saran Hospital, which is a government hospital specializing in children's diseases. The child was diagnosed as suffering from cerebral palsy in addition to a congenital anomaly of the ears, and her linguistic abilities seem limited. Perhaps the stigma of having a disabled daughter makes Pushpa's life difficult.
>
> Every week, for the three weeks during which we have already conducted and codified the weekly survey for this household, she has been to visit the local practitioner who displays that he has an M.B.B.S. degree on the board outside his little shop. According to her, the doctor has never needed to measure her blood pressure because he has such diagnostic skill that he can "read" the blood pressure by just looking at her face. Every week she receives a cocktail of medicines from him. It is quite a common practice for practitioners in many low-income neighborhoods to dispense the medicines they prescribe in small envelopes divided according to dosage—so it is not easy to know what the medicines are. However, it is evident that what she is being treated for is not "low BP." From interviews with some of the practitioners in this area, my guess is that she might have been given paracetamol or analgesics.

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> It is also entirely possible that occasionally she may be given steroids: she feels very well after taking the medicine for a day or two and then falls into sadness and becomes listless.[62]

How are we to think of the category of "low blood pressure," which seems to have replaced any categories that might be described as "folk" categories, such as the liver or the heart, as the signifier of the whole gamut of conditions under which the poor have to live? It is evident that the health of the poor cannot be thought of in isolation from the circulation of biomedical categories of disease or from the drugs manufactured and dumped not only by the pharmaceutical industry but by the spurious industry of drugs from which many of the practitioners in the informal system probably buy the medicines that are then given to the poor.[63] Thus, what we find is a mélange of categories, drugs, and practices, which makes it impossible to distinguish between the "native" categories of health and illness and the "imposed" categories of biomedicine.

Pushpa's narrative presents a case in which the biomedical practices endanger the health of the individual. The frequent use of inappropriate antibiotics for the common treatment of childhood diseases not only endangers children but poses a grave threat to the environment in which microbial resistance is becoming a major problem.

> Priti is a seven-month-old baby. Though her parents are both nonliterate, they are quite aware of the importance of immunization. By using the category of *janam tika* (childhood vaccines), they make a distinction between the DPT shots and the OPV doses she has received versus the injections that the local doctors give when she falls ill. In the weekly morbidity surveys it was revealed that the child has been ill with diarrhea, respiratory infection, or fever every week. There are two different practitioners in the area that the parents visit. The first is a doctor working in a government hospital, who runs a clinic in the evening for two hours in this locality. The second is a holder of a recognized university degree in Electrohomeopathy, which is based upon treatment with plant extracts. The latter is available almost until 10 p.m. in his clinic every day. The baby was taken to the first doctor initially and then to the second doctor because the parents were under a time constraint and also felt that she was getting repeated episodes of

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illness. For each of these infections the baby was given antibiotics: Metrogyl for diarrhea, Ampicillin for cough, and Amoxycillin for fever. This was in addition to certain other medicines, probably paracetamol and some local remedies made by the doctor. In addition, the second doctor gave her a medicine for protecting her against the evil eye.

In an interview with the second doctor, I asked what kind of medicines he prescribed for his patients. In addition to the plant extracts, he said, he gave paracetamol and antibiotics because they were more effective. He knew the name of three antibiotics for fever: Septron, Ampicillin, and Amoxycillin. For diarrhea he prescribed either Getamycin or Metrogyl. Interestingly, there does not seem to be much difference between the medicines prescribed by the qualified government doctor who runs a private clinic in the evenings and the doctor practicing alternative medicine. The first doctor, whom I have not been able to interview, seems to have been better informed, but he also prescribed antibiotics for what appeared to be ordinary diarrhea from the description of the symptoms. No advice was given on the completion of the course, so in each case the baby was given medicine for a day or two and then the parents stopped when they thought that the child was better.

The case of Meena is similar. She is eleven years old and has perforated eardrums. Because of repeated pus formation in one ear, she had been often treated by local doctors. The child was taken to a government hospital two years ago where she was correctly diagnosed and advised to undergo surgery, but the parents could not get a date because of overcrowding. The child, meanwhile, has been getting repeated ear infections for the last six years. A perusal of her medical documents at the government hospital, which were available to her parents, revealed that the disease had developed resistance to nine known antibiotics. Yet because of the fact that she was often taken to the local practitioner who was not aware of microbial resistance as a problem, she had been receiving inappropriate antibiotics for weeks.[64]

It would be easy to dismiss such cases as simply the results of inadequate regulation of medical practices—the Delhi Medical Association has been demanding that the legislature should pass the Quackery Bill, which would make the practice of

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allopathic medicine by those not qualified to do so (including practitioners in alternative medical systems) a criminal offense. However, our studies suggest that the differences between various kinds of practitioners in the localities in which the poor reside are not strongly marked. In fact, the patients going to the qualified practitioners often end up paying more because of unnecessary diagnostic tests that are recommended in addition to unnecessary medication. Examples include referral to a diagnostic laboratory for tests that had already been conducted in another laboratory and inappropriate x-rays as well as computerized tomography (CT) scans. We have found patients who have been receiving paracetamol for years: sometimes their symptoms indicate somatization of psychiatric symptoms, sometimes the sheer exhaustion of managing everyday living in conditions of poverty, and other times there maybe an underlying disease, such as tuberculosis or typhoid, that has gone untreated.

It would appear, then, that the boundaries between what is private and what is public in health are difficult to determine. One consequence of this finding for policy-making is that structural programs that recommend a greater partnership between providers in the private sector and those in the public governmental sector may be captive to a picture of practitioners in the private sector that may be valid only in the more affluent sectors of society. Thus, if we continue to think in terms of the public/private dichotomy in devising policy and attributing the occurrence of chronic and noncommunicable diseases to the private decisions of individuals, we may end up seriously underestimating the force of global and market processes in the production of these diseases. Restructuring health care on the basis of abstract principles about individual responsibility for personal decisions regarding health care may have adverse consequences for the health of the poor unless we seriously rethink the public/private dichotomy in this sphere as has been done by feminist scholars in other spheres.

One might wish to pause here and consider the following: while these may be interesting questions for policy and research, do they hold any ethical implications? I suggest that these issues hold implications for both anthropology and medi-

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cal ethics, broadly conceived. Discussion in anthropology on how to reorient itself in relation to new objects of inquiry, since the older distinction between so-called primitive and modern societies has collapsed, cannot be oblivious to the profound changes taking place in the definition of what constitutes humanity and what constitutes nature. Bioethics is faced with a choice: should it continue as a branch of the practice of biomedicine in the West, which gives it coherence and allows it to function in the shadow of the law within which such concepts as consent, disclosure, and truth-telling take their meaning, or should it address these larger questions relating to the tensions and the symbiosis between health as a public good and health as a private resource?

In a recent essay, Gísli Pálsson and Paul Rabinow see the problem for anthropology as that of reinventing itself in the face of a nature very different from that experienced by previous generations. "For one thing," they say, "biotechnology has revolutionized the capacity for altering DNA material, raising new and fundamental 'anthropological' questions. Although anthropologists have argued for a long time that the human body and nature are inextricably social . . . it is a cliché today to say that a new power to modify them is with us and that they are increasingly commodified and subject to market exchange."[65] They locate this tension in the ethics and politics of representation, especially through their discussion of controversies surrounding the project to map the genome of the Icelandic people by DeCode Genetics, a biotechnology company. A powerful underpinning of this work lies in the idea that the capacity to modify nature according to social norms requires a new way to address issues of political and ethical representation.[66] But there is another way in which nature is being modified: through the kind of biomedical practices that are leading to the emergence of antimicrobial resistance. These modifications are not modeled on social norms, nor are they well understood. They are the unintended consequences of human actions and uncontrolled exchanges of genetic materials occurring in nature. These too hold the ominous potential of changing the experience of disease in new and unpredictable ways. In light of this, the ethics of fieldwork must surely face up to the fact that the

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relation between anthropologist and informant can be modeled neither on "rapport" nor on "complicity" as suggested recently by George Marcus.[67] For instance, we found in our own fieldwork that in collecting data on morbidity it became imperative to make new choices available to the community with which we are working because of the life-threatening potential of some of their practices. If the relation between expert knowledge and democratic norms poses difficult issues for biotechnology in the fields of new reproductive technology and the genome project (with which anthropologists continue to engage), the nature of this challenge in relation to the everyday practices of biomedicine in low-income countries is of an altogether different kind. The issue in this context is rarely that of our stake in "humanity" or "the human condition" as many have supposed but rather how we can make institutions concerned with large issues of "human dignity" or "human rights" responsive to the small happenings in local communities far away from the eyes of the media or of new technologies—happenings that could nevertheless have vast consequences for our experience of the body, nature, or society.

The intersections of such fields as bioethics and anthropology,[68] or molecular biology and anthropology,[69] appear to pose daunting challenges. We are likely to be less certain about the philosophical foundations on which the new concerns arising from these intersections can be grounded. The individualistic models of bioethics hold as little promise as the simple communitarian models of local worlds constructed by anthropologists or the well-honed concepts of political and ethical representation, which work better in this context for fully literate and affluent societies. Self-perceived categories to represent disease, such as explanatory models or illness narratives, are extremely important, because they make present the connections between individual bodies and social bodies. We must understand, though, that such categories have also evolved through the experiences of norms and institutions of biomedicine.[70] Rather than a prior commitment to "the native point of view," it may be that the way to respond to the suffering of such persons as Pushpa, Meena, and Priti in the most ordinary of circumstances might ground such questions better than re-

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course to any grand narratives of human dignity, personal autonomy, and other such concepts. Such I feel is the nature of this challenge.

ACKNOWLEDGMENTS

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ENDNOTES

[1]Arthur Kleinman, *Writing at the Margin: Discourse between Anthropology and Medicine* (Berkeley: University of California Press, 1995); Kleinman, "Experience and its Moral Modes: Culture, Human Condition, and Disorder," in *The Tanner Lectures on Human Values* (Salt Lake City: University of Utah Press, 1999), 357–420; Patricia A. Marshall, "Bioethics in Anthropology: Perspectives on Culture, Medicine and Morality," in *Medical Anthropology: Contemporary Theory and Method* ed. Carolyn F. Sargent and Thomas M. Johnson (Westport, Conn.: Praeger, 1996); J. M. Muller, "Anthropology, Bioethics and Medicine: A Provocative Trilogy," *Medical Anthropological Quarterly* 8 (4) (1994): 448–467.

[2]T. L. Beauchamp and R. R. Faden, "Informed Consent II: Meaning and Elements for Informed Consent," in *Encyclopedia of Bioethics,* rev. ed., ed. Warren T. Reich (New York: Macmillan, 1995), vol. 3, 1240. See the series of papers under the general title of "Bioethics for Clinicians" edited by Peter Singer in the *Canadian Medical Association Journal* (1996 and 1997).

[3]See the contribution of Renée C. Fox in this volume.

[4]D. Macer, "Bioethics in and from Asia," *Journal of Medical Ethics* 25 (4) (1999): 293.

[5]Renu Addlakha and Jan Seeber, *Health Ethics in South East Asia: Vol. III* (New Delhi: WHO, 1999).

[6]It is not my case that Eastern philosophical systems may not have the resources to reconfigure bioethics in a new way. However, simply providing quotations from authorizing texts, such as the Upanisads (Vandana Shiva, "Bioethics: A Third World Issue," 1997; available on website <http://csf.colorado.edu/elan/jun97/0026.html>, downloaded on 14 September 1999) or the Constitution (N. Katuriarchi, R. Lie, and J. Seeber, *Heath Ethics in South East Asia: Vol. 1* [Delhi: WHO, 1999]), is not likely to advance matters further.

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[7]Steven Epstein, *Impure Science: Public Action and the Politics of Knowledge* (Berkeley: University of California Press, 1996).

[8]See David Arnold, *Colonizing the Body: State, Medicine, and Epidemic Diseases in Nineteenth-Century India* (London: Oxford University Press, 1993); Veena Das and Abhijit Dasgupta, "The Cholera Vaccine: Trajectories in Contemporary Bengal," *Economic and Political Weekly: Special Issue on Social Science and Immunization* (in press); Mark Harrison, *Public Health in British India: Anglo-Indian Preventive Medicine, 1859–1914* (Cambridge: Cambridge University Press, 1994); Kavita Misra, "The Productivity of Crisis: On the Relation between Science and State in Colonial India," *Economic and Political Weekly: Special Issue on Social Science and Immunization* (in press); and Harish Naraindas, "Care, Welfare, and Treason: The Advent of Vaccination in the Nineteenth Century," *Contributions to Indian Sociology* (32) (1998): 1.

[9]Arnold, *Colonizing the Body*; Richard N. Cooper, "International Cooperation in Public Health as a Prologue to Macroeconomic Cooperation," in Cooper et al., eds., *Can Nations Agree?* (Washington, D.C.: Brookings Institute, 1989); Harrison, *Public Health in British India.*

[10]CISET (Committee on International Science, Engineering, and Technology), *Global Microbial Threats in the 1990s*, working group on Emerging and Reemerging Infectious Diseases (Washington, D.C.: National Science and Technology Council, 1995).

[11]The literature on reemerging infectious diseases is vast; the emergence of resistant strains of tuberculosis and a new strain of cholera in 1992 have been cause for special concern in India. See Cholera Working Group, "Large Epidemic of Cholera like Disease in Bangladesh caused by Vibrio *cholorae* 0139 synonym Bengal," *Lancet* 24 (1993): 387–390; A. Kumar, "Microbial Resistance to Drugs—A Universal Problem in Need of Comprehensive Approach," *National Medical Journal of India* 10 (5) (1997): 221–224; G. B. Nair et al., "Vibrio *cholorae* 0139 Bengal: The New Serogroup Causing Cholera," *Reviews in Medical Microbiology* 7 (1) (1996): 49–51; R. Prabhakar, "Tuberculosis—The Continuing Scourge of India," *Indian Journal of Medical Research* 103 (1996): 19–25; and N. Siddiqui et al., "Molecular Genetic Analysis of Multi-drug Resistance in Indian Isolates of Mycobacterium Tuberculosis," *Memorias do Instituto Oswalsdo Cruz* 93 (5) (1998): 589–594.

[12]Stuart B. Levy, *The Antibiotic Paradox: How Miracle Drugs are Destroying the Miracle* (New York: Plenum Press, 1992); Stuart B. Levy, J. Burke, and E. Wallace, "Antibiotic Use and Antibiotic Resistance Worldwide," *Review of Infectious Diseases* (9) (1987).

[13]Lincoln C. Chen, Tim G. Evans, and Richard A. Cash, "Health as a Public Global Good," in *Global Public Goods: International Cooperation in the 21st Century,* ed. Inge Kaul, Isabelle Grunberg, and Marc A. Stern (New York: Oxford University Press, 1999), 284–304.

[14]Ibid.

[15]The question of priority is also influenced by what is technologically and administratively feasible. This being granted, it is often overlooked that feasibility cannot be defined in a vacuum. It is itself a function of the imagination of

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a particular kind of future. If, for instance, the emphasis is on the eradication of a particular disease from society and nature, then not many diseases can be candidates. If, on the other hand, the concern is with the reduction of case load or the case-fatality ratio of a disease, then the policy implications and technological requirements are quite different.

[16]Chen, Evans, and Cash, "Health as a Public Global Good," 292.

[17]Kleinman, "Experience and its Moral Modes."

[18]See Veena Das, Ranendra K. Das, and Lester Coutinho, eds., *Social Science and Immunization,* special issue of *Economic and Political Weekly* (in press). This work was conducted as part of an international project on immunization practices in nine countries and was coordinated by Pieter Streefland and Paul Greenough. My colleague, Ranendra Kumar Das, and I directed the country study on India. Following this study, a group of researchers primarily based in Delhi formed a group under the auspices of the Institute for Socioeconomic Research in Democracy and Development and are engaged in researching the burden of disease and health-seeking behavior in both urban and rural settings in India. We are grateful to the governments of the Netherlands and Denmark for their support of the project on *Social Science and Immunization* for the India country study.

[19]But see Fredrique Appfel-Marglin, "Eradication of Smallpox, the Cult of Sitala, and Ecological Politics," *Soumen Anthropology* 4 (1986): 160–181, and Paul Greenough, "Intimidation, Coercion, and Resistance in the Final Stages of the South Asian Small Pox Eradication Campaign, 1973–1975," *Social Science and Medicine* 41 (1995): 633–645, for important critiques of this position.

[20]Statement issued by Dr. Terrell M. Hill, senior health advisor in UNICEF's division. Statement available on website <http://hoshi.cic.sfu.ca/abstracts/Abstract17.txt>, downloaded on 14 September 1999.

[21]R. H. Handerson, "Immunization: Going the Extra Mile," in *The Progress of Nations Report* (New York: UNICEF, 1998).

[22]Despite claims made by WHO and UNICEF, this is difficult to judge because detailed statistics on childhood deaths attributed to vaccine-preventable diseases were not available until recently—these were reported under the general category of infectious diseases. Further, mortality for vaccine-preventable diseases may decline because of the availability of better nutrition or more effective treatment. Even now there are reasons to take the data on the incidence of vaccine-preventable diseases and the case-fatality ratio with caution, as will become clear later. In any case, 40 percent of infant mortality in India occurs in the first twenty-eight days—only part of which can be tackled through Tetanus Toxoid vaccine administered to the mother during pregnancy. Some attempts have been made to assess the impact of immunization on the reduction of mortality, but these face the same problems of the availability of reliable data. See M. A. Koenig, V. Fauveau, and B. Wolyniak, "Mortality Reduction from Health Interventions: The Case of Immunization in Bangladesh," *Population and Development Review* 17 (1) (1991): 87–104.

[23]Illana Lowy, "Yellow Fever in Rio de Janeiro," *Medical History* 34 (1990): 144–163.

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[24]Mark Nichter and Mimi Nichter, *Anthropology and International Health: Asian Case Studies* (Amsterdam: Gordon and Breach, 1996).

[25]Peter Aaby, "Assumptions and Contradictions in Measles and Measles Immunization Research: Is Measles Good for Something?" *Social Science and Medicine* 4 (15) (1995): 673–686; Peter Aaby and B. Samb, "Measles and its Control: Dogmas and New Perspectives," in *Health and Disease in Developing Countries*, ed. Kari S. Lankinen et al. (London: Macmillan Press Ltd., 1994); Harold V. Wyatt, "Proactive Poliomyelitis: Neglected Clinical Observations from 1914 to 1950," *Bulletin of History of Medicine* 55 (1981): 543–557; Wyatt, "Unnecessary Injections and Paralytic Poliomyelitis in India," *Transactions of the Royal Society of Tropical Medicine and Hygiene* 86 (1992): 546–549; Wyatt, "Mothers, Injections and Poliomyelitis," *Social Science and Medicine* 35 (1992): 595–598.

[26]Theodore M. Porter, *Trust in Numbers: The Pursuit of Objectivity in Science and Public Life* (Princeton, N.J.: Princeton University Press, 1995).

[27]The use of the first person plural here refers to the collective work done by the entire Indian team on the project on *Social Science and Immunization.*

[28]Ranendra K. Das and Purnamita Dasgupta, "Childhood Immunization in India: A Macro Perspective," *Economic and Political Weekly: Special Issue on Social Science and Immunization* (in press).

[29]Ibid.

[30]M. A. Zacher, "Health Surveillance as a Public Good," in *Global Public Goods: International Cooperation in the 21st Century*, ed. Kaul, Grunberg, and Stern, 272–283.

[31]Lester Coutinho, Suman Bisht, and Gauri Raje, "Numerical Narratives and Documentary Practices: Vaccines, Targets, and Reports of the Immunization Program," *Economic and Political Weekly: Special Issue on Social Science and Immunization* (in press).

[32]See Das and Dasgupta, "Childhood Immunization in India"; Coutinho, Bisht, and Raje, "Numerical Narratives and Documentary Practices"; Jishnu Das and Saumya Das, "The Provision of Preventive Health Care: The Case of Immunization," mimeo, 1999. For instance, in their study of preventive health care in Salang, a village in the hilly regions of Garhwal, Das and Das report that, matching age for the number of doses of antigens received, 51 percent of children in the village were partially immunized and 45 percent were unimmunized. These figures point to areas where coverage is low and show that aggregate figures for a country can hide significant variation.

[33]See UNICEF, "The State of the World's Children 1999," available on website <http://www.unicef.org/sowc99/>.

[34]I dare to state this despite confident assertions in the UNICEF documents, which give precise figures in the reduction of child mortality attributed to immunization programs. The very precision of the figures is suspect. Handerson states that "Deaths from those six diseases (measles, tetanus, whooping cough, tuberculosis, polio and diphtheria) have been slashed by 3 million a year, and at least 750,000 fewer children are left blind, perplexed, or mentally

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disabled." Handerson, "Immunization: Going the Extra Mile." Contrast this with the careful computation of the burden of disease in Murray and Lopez, who, despite a massive effort covering documentation from all Primary Health Centers in Maharashtra, were compelled to caution that the data on India were not reliable. Christopher J. L. Murray and Alan D. Lopez, *The Global Burden of Disease Study* (Cambridge, Mass.: Harvard School of Public Health, 1998).

[35]See adverse reaction testimonials downloaded from website <http://www.unc.edu/~aphillip/www/vaccine/stories.htm> on 14 September 1999.

[36]Terrel M. Hill, "Synthesis of Lessons Learned: Experience of Universal Childhood Immunization," 1998, downloaded from website <http://hoshi.cic.sfu.ca/abstracts/abstracts/Abstract17.txt> on 14 September 1999.

[37]Veena Das, "Hunger," *Seminar* (1) (1998): 67–75; Veena Das, "Food Security and Secure Livelihoods: A Case Study of Bilaspur Division," mimeo, 1998.

[38]I should note here that the Pahadi Korvas are classified in administrative discourse as a "primitive tribe" and are entitled to certain special developmental assistance over and above that available to members of "scheduled tribes" according to constitutional provisions. The headman was also a member of a scheduled tribe. Hence the indifference to the Pahadi Korvas did not stem from marked differences in status and rank but from differential control over the resources in the village.

[39]India is relatively self-sufficient in vaccine production. The universal program in immunization has received logistic support from UNICEF but it does not depend upon external aid. Where the program is entirely funded by external aid, as in some African countries, the program can become hostage to international conflicts. Thus, the programs devised by international agencies such as UNICEF and WHO are themselves vulnerable to international politics over which they may not have control.

[40]Byron Good, *Medicine, Rationality, and Experience: An Anthropological Perspective* (Cambridge: Cambridge University Press, 1994).

[41]Sjaak van der Geest and Susan Reynolds Whyte, eds., *The Context of Medicines in Developing Countries* (Dordrecht: Kluwer, 1988); Nichter and Nichter, *Anthropology and International Health.*

[42]M. Mamdani and G. Walker, *Essential Drugs and Developing Countries: A Review and Selected Annotated Bibliography,* EPC publication no. 8 (London: School of Hygiene and Tropical Medicine, 1985).

[43]Nina L. Etkin and L. Tan, eds., *Medicines: Meanings and Contexts* (Philippines: Health Action Network, 1994); Sjaak van der Geest, Susan Reynolds Whyte, and A. Hardon, "Anthropology of Pharmaceuticals: A Biographical Approach," *Annual Review of Anthropology* 25 (1996): 153–178.

[44]Etkin and Tan, *Medicines: Meanings and Contexts,* 2.

[45]van der Geest and Whyte, *The Context of Medicines in Developing Countries,* 9.

[46]Paul Farmer, *AIDS and Accusation: Haiti and the Geography of Blame* (Berkeley: University of California Press, 1992).

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[47]Nancy Scheper-Hughes, *Death without Weeping: The Violence of Everyday Life in Brazil* (Berkeley: University of California Press, 1992).

[48]Jishnu Das and Saumya Das, "Health Seeking and the Poor: Evidence from India," mimeo, 1999.

[49]A. M. Alam, F. U. Ahmed, and M. E. Rahman, "Misuse of Drugs in Acute Diarrhea in Under-Five Children," *Bangladesh Medical Research Council Bulletin* 24 (2) (1998): 27–31.

[50]See also Anant Phadke, *Drug Supply and Use* (New Delhi: Sage Publications, 1998).

[51]Etkin and Tan, *Medicines: Meanings and Contexts.*

[52]M. A. Domin, "Highly Virulent Pathogens—A Post Antibiotic Era? *British Journal of Theatre Nursing* 8 (2) (1998): 14–18.

[53]Das and Das, "Health Seeking and the Poor."

[54]Marc Augé, *An Anthropology for Contemporaneous Worlds,* trans. Amy Jacobs (Stanford: Stanford University Press, 1999), 8.

[55]Paul Farmer, *Infections and Inequalities: The Modern Plagues* (Berkeley: University of California Press, 1999).

[56]Renée C. Fox and Judith P. Swazey, *The Courage to Fail: A Social View of Organ Transplants and Dialysis,* 2d rev. ed. (Chicago: University of Chicago Press, 1978); Margaret Lock, "Transcending Mortality: Organ Transplants and the Practice of Contradictions," *Medical Anthropology Quarterly* 9 (3) (1995): 390–399.

[57]Rayna Rapp, *Testing Women, Testing the Fetus: The Social Impact of Amniocentesis in America* (New York: Routledge, 1999); Marilyn Strathern, *After Nature: English Kinship in the Late Twentieth Century* (Cambridge: Cambridge University Press, 1992).

[58]Gísli Pálsson and Paul Rabinow, "Iceland: The Case of a National Human Genome Project," *Anthropology Today* 15 (2) (1999): 14–18; Paul Rabinow, *Making PCR: A Story of Biotechnology* (Chicago: University of Chicago Press, 1996); Paul Rabinow, *French DNA: Trouble in Purgatory* (Chicago: University of Chicago Press, 1999).

[59]For an important critique of the manner in which the concept of belief is deployed in medical anthropology, see Good, *Medicine, Rationality, and Experience.*

[60]One of the most interesting anthropological studies that shows the entanglement of these processes in the case of India is Lawrence Cohen, *No Aging in India: Alzheimer's, The Bad Family, and Other Modern Things* (Berkeley: University of California Press, 1998).

[61]The team of researchers is Ranendra K. Das, Renu Addlakha, Jishnu Das, and me, and is assisted by Charu Kumar, Shashi Bhushan Singh, and Bhrigupati Singh. We are conducting a pilot study of forty households in two neighborhoods in Delhi. A weekly morbidity survey on the incidence and prevalence of disease, the type of medical care, and the cost of health care is conducted. A

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verbal examination of the cases with two physicians, Dr. Karuna Taneja and Dr. Samir Singh, helps us to arrive at some judgment about the likely diagnosis, the efficacy of treatment, and the necessity of the expenditure incurred. Patients who are judged to be at risk of irreversible damage if present regimes of treatment continue are given a choice to consult either of the two doctors free of charge.

[62]In a similar study in Salang, a remote access village in the hilly region of Garhwal, Jishnu Das and Saumya Das found that steroids were given by the practitioners in the informal health sector for such conditions as weakness. See Das and Das, "Health Seeking and the Poor."

[63]In one case we found a patient who had been taking a drug called APC for thirty years. It appears that this combination of Anacin, paracetamol, and codeine, which was commonly used in the 1930s and was available as a nonprescription drug, is still being manufactured and sold through the informal sector of health care, though we do not know the composition of this medicine.

[64]For a detailed study of the use of inappropriate medications in a district in India, see Anant Phadke, *Drug Supply and Use* (Delhi: Sage Publications, 1998).

[65]Pálsson and Rabinow, "Iceland: The Case of a National Human Genome Project," 16–17.

[66]See also Rabinow, *Making PCR,* and Rabinow, *French DNA.*

[67]George E. Marcus, *Ethnography through Thick and Thin* (Princeton, N.J.: Princeton University Press, 1998).

[68]Kleinman, "Experience and its Moral Modes"; Fox and Swazey, *The Courage to Fail.*

[69]Pálsson and Rabinow, "Iceland: The Case of a National Human Genome Project."

[70]Arthur Kleinman, *Patients and Healers in the Context of Culture: An Exploration of the Borderland Between Anthropology, Medicine, and Psychiatry* (Berkeley: University of California Press, 1980); Kleinman, *The Illness Narratives: Suffering, Healing, and the Human Condition* (New York: Basic Books, 1988).

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Donald Davidson and other philosophers speak of the difference between actions and events. I find the distinction useful here. Actions have actors; actions express actors. Actions have reasons; actors are responsible for what they do, and character is destiny. But events happen *to* people. Events have no reasons, only causes.

Narratives motivated by karma convert all events into actions; in them everything has a reason, as in the Mahabharata. But there is much in human reality that is not controlled by human beings—accident, social and economic institutions, nature itself, especially nature in its most intimate human form, one's own and others' bodies. The uncontrollable part of nature cannot be rationalized, especially in the moment of crisis. It can only be accepted or watched, laughed at or sidestepped and bypassed by human ingenuity. In these oral tales, this reality is not reasoned away but faced. Here actions, human actions, are seen as events. They have causes, no reasons. By enduring them and watching for a moment of change that is the apt moment for action, and acting then, usually speaking out, telling one's own story, one comes through. That's why many of these tales end with the heroine telling her own story to "a significant other" (often through a device, like a talking doll or a lamp), resolving the crisis, ending her separation, reuniting with her husband and her kin. The tale then becomes her story.

A. K. Ramanujan

From "Telling Tales"
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Lawrence Cohen

Where It Hurts: Indian Material for an Ethics of Organ Transplantation

PROLOGUE: THE SCAR

WE ARE SITTING in a one-room municipal housing-project flat in a Chennai slum, in a room filled with photographs of the man of the house posing with Tamil political leaders. His wife, one of the persons I am interviewing this June 1998 morning, all of whom had sold a kidney several years earlier for 32,500 rupees (roughly $1,200 at the time of sale), is speaking about why poor people get into debt. Chennai used to be called Madras, and it has become the place where people come in search of a "selling-their-kidneys-to-survive" story. This woman has invited us—myself, the hospital orderly Felix Coutinho who hooked me up with her, and the four other sellers we have found—to use her place for interviews. All of the sellers are women, and all but one have gone through Dr. K. C. Reddy's clinic to have the operation. "Operation" is one of the few words I recognize in the Tamil conversation that Mr. Coutinho is translating. I am used to working in north India and the United States, but neither English nor Hindi is of particular use at this moment. As they are cut out from the flesh, organs reconstitute the spaces of bodily analysis, and to delineate these spaces I have found myself continually moving about and ever more reliant, uncomfortably, on translation.[1]

Dr. Reddy has been India's most outspoken advocate of a person's right to sell a kidney. His practice—until 1994, while it was arguably still legal to remove someone's kidney without

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a medical reason—was apparently exemplary: education for potential sellers on the implications of the operation, two years free follow-up health care, and procedures to avoid kidney brokers and their commission. My anthropological colleague Patricia Marshall, on her own and with the Omani transplant surgeon Abdullah Daar, studied the practice of Reddy and his colleagues.[2] She did not find evidence of the often-reported practices of cheating, stealing from, or misinforming sellers. Marshall introduced me to Reddy and to the general practitioner who had run his follow-up clinic for local sellers.

When I first visited the follow-up clinic, an estate with an abandoned air set back from the Poonamalai High Road, I met Coutinho sitting on the verandah with several other orderlies. He had previously been the go-between hooking up sellers with the clinic and knew where to find them. We talked for a while: there were not many patients. The follow-up clinic had closed when Reddy shut down his program in the wake of India's 1994 Transplantation of Human Organs Act, which made the selling of solid organs unambiguously illegal, authorized the harvesting of organs from the bodies of persons diagnosed as brain dead, and forbade the gift of an organ from a live donor other than a parent, child, sibling, or spouse. There were exceptions, approved by Authorization Committees set up in each state that implemented the Act to ensure that the donor was some kind of relation or close friend. *Frontline,* a Chennai-based newsweekly, had published an article the year before documenting how easily these committees were circumvented.[3] As long as the paperwork was in order, the investigative team argued, it was virtually impossible for committee members to differentiate an altruistic donation from a sale masquerading as such.

Coutinho and I sat on the verandah and talked about my project. He was interested in helping out, he said, because he, too, was a social worker. Later he told me about his project, the LOVE Foundation, a home for the destitute elderly that he and some friends from his church had set up. Would I consider visiting the LOVE home and helping it out? We agreed to meet the next morning to visit Ayanavaram and Ottery slums, and

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when I had had enough of kidneys for me to talk to the Secretary of LOVE.

Many investigators had taken this route before, into the Chennai slum: the abject stories, the repeated and identical image of a man or a woman turning his or her flank to the camera and tracing the line of the scar. The slum of choice was Villivakkam, nicknamed "Kidneyvakkam" because so many of its residents had undergone the operation. Raj Chengappa, senior deputy editor at the newsmagazine *India Today,* told me that after breaking the Villivakkam story in the early 1990s with an article called "The Great Organs Bazaar," he was deluged with calls from American and European based media.[4] Villivakkam gothic became routinized, as in its wake of scandal and shock did a counter-narrative in which sellers were informed agents making rational choices under unenviable but real conditions. Information brokers joined organ brokers in leading filmmakers and reporters—and, following them, anthropologists, ethicists, and medical fact-finding teams—along well-rutted paths to predictable stories. Depending upon the need, terrains of violence or of agency and reason materialized. There was material in the slum for all manner of social workers.

* * *

Few of the growing number of Villivakkam experts have commented on what is to the outsider a pronounced feature of the slum's topography: it is saturated with pawnshops where moneylenders buy and sell gold and other precious items. Outside many shops in the slum's central shopping area are boards noting the day's buying and selling prices. Women in particular examine jewelry they are considering buying to consolidate their earnings or bargain over the money and credit earned by pawning their gold. There are few banks.

I worried that Villivakkam might not be the place to begin, given the neighborhood's media glut and my sense of the emergence of information brokers offering investigators whichever version of the trade they seem to want to find. I asked Coutinho whether there were other neighborhoods, where one might

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learn something new. We ended up in the Ayanavaram municipal projects, in the room with the political pictures, listening to one woman after another recount her story. Similar stories, but different in quality from the various public accounts, *neither* tales of graphic exploitation nor heroic agency. There were obvious biases: Coutinho was identified with Reddy, and his presence might have dampened any accounts of malpractice or exploitation. Conversely, I was signifiably well-off—dressed like the middle class, foreign, and white—and the possibility of future patronage might have heightened accounts of poverty and disappointment. We came in the late morning, when many of the women were back from domestic service but the men were still out working or looking for day jobs; we may have overestimated the proportion of women to men sellers. But the one man we interviewed as well as all of the women said that few men in this neighborhood had undergone the operation. In each neighborhood, the stories we heard varied in the details of a body and its particular situation, but shared several common threads.[5]

What was common: I sold my kidney for 32,500 rupees. I had to; we had run out of credit and could not live. My friend had had the operation and told me what to do. I did not know what a kidney was; the doctors showed me a video. It passes water; it cleans the blood. You have two. You can live with one, but you may get sick or die from the operation or from something later. You have to have the family planning operation because without a kidney childbirth is very dangerous. I had already had *that* operation.

This, too: What choices did I have? Yes, I was weak afterwards, sometimes I still am. But generally I am as I was before. Yes, I would do it again if I had another to give. I would have to. That money is gone, and we are in debt. My husband needs his strength for work, and could not work if he had the operation. Yes, I also work.

* * *

Around us are several pictures of the husband meeting with the beloved late chief minister of Tamil Nadu, known by his initials:

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MGR. The husband organizes for the All India Anna Dravida Munnetra Kazhagam party in the housing project. The wife says he had been better connected with leaders in the days when MGR was alive. She nods toward MGR in the photo: "He needed a kidney, too," she says. "He was dying, and received one from his niece; they did the operation in America. At that time, I did not know about kidneys. If I had, I would have given him *both* of mine."

Why Chennai? Deeper poverty and debt are found elsewhere, but the urban south was the first fertile ground for organ harvesting. Part of the answer is not surprising. Both primary health care and tertiary medical innovation are more developed in south India, leading not only to some of the earliest transplantations in India but also to greater access to medical institutions for persons across class lines.[6] For the question of contemporary kidney sales in Chennai, additionally relevant is the fact that the relation of medicine to what we might term the constitution of the citizen's body is gendered.

What might such a link between gender, citizenship, and the possibility of transplantation entail? Cecilia Van Hollen has studied the high usage of reproductive medicine and family planning by poor women in Chennai and other cities in the state of Tamil Nadu.[7] The situation differs significantly from much of north India, where women have been less likely to utilize state biomedical interventions like tubal ligations.[8] Many poor women in Chennai incorporate surgery and other obstetric and family-planning procedures into their lives, frequently electing extensive medical intervention. Van Hollen's findings suggest the ubiquity and intensive character of this medicalization as central to any account of agency in women's encounters with the state. *What they said* in Ayanavaram: I already had that operation. They told me I needed to have it before I could have the kidney operation, *but I already had it.*

Thus, most women have chosen to undergo tubal ligation before the decision to sell a kidney is imagined. The emergence of Chennai's various "Kidneyvakkams" must be located in the *prior operability* of these bodies. The operation here is a central modality of citizenship, by which I mean the performance of agency in relation to the state. It is not just an example of

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agency; it is agency's critical ground. In other words, having an operation for these women has become a dominant and pervasive means of attempting to secure a certain kind of future, to the extent that means and ends collapse: to be someone with choices is to be operated upon, to be operated upon is to be someone with choices. "Operation" is not just a procedure with certain risks, benefits, and cultural values; it confers the sort of agency I am calling citizenship.[9]

Intriguingly, in these interviews the operation was said to weaken men more than women. A prior moment of contest over operability was, of course, the nationwide "Emergency" more than two decades earlier with its legacy of coercive family-planning operations, and particularly vasectomies.[10] Current accounts of the operation's greater danger to men draw upon memories of that earlier time, as well as upon a more generalizable phenomenology of male anxiety in the face of imagined female regeneration.[11] In these women's accounts of their husbands' concerns, an operable citizenship came at far higher risk to men: it literally "unmanned" them. Regions like the "kidney belts" of rural Tamil Nadu feeding the Bangalore industry, where more sellers were men than in Chennai, often comprised settlements of mostly male migrant workers paying off large debts in the wake of the collapse of the booming power-loom industry. Women were back in the village, and were less likely than urban women to have been hospitalized in childbirth or to have had procedures like tubal ligations.[12]

I would have given him both of mine: if the gendered terms of citizenship in Chennai are set in part by one's operability, and if women here are the primary sites of the operation, then this woman's proposed gift of both of her kidneys to MGR can be rethought. Her gesture momentarily seems to redeem the operative losses of citizenship by framing them as a critical gift that might have saved the famous leader. Our hostess transforms her second operation from an abject transaction to an act that reconstitutes Tamil Nadu's beloved late chief minister. A young man, the son of another woman who sold her kidney, complained to us later that day that other boys call him names: "Your mother is a kidney seller!" The current order of the commoditization of everything, in which the operation trans-

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forms this mother into a prostitute, is countered here by resuscitating MGR as the politician-father and the idealized order he has come to represent. In invoking MGR's need for a kidney, this seller rescripts her sale into a gift to the Tamil leader that revives the idealized social relations of that time and renders all such sales unnecessary.

* * *

Within the terms of such an imaginable gift, what language would pain take? One of the women in the room offers the beginning of an answer. Her operation, she says, caused her body to hurt. "It still hurts." She points to her flank, to the scar. "It hurts there." I ask her, through Coutinho, to describe the pain. There is no data in India on the effects of nephrectomy for these very poor sellers, most of whom lack long-term primary care. I begin to ask her more and more specific questions, sensing a symptom.

She looks at me, then at Coutinho. She had been talking, before my asking her about this pain, about her husband: a story of sporadic work, frustration, and drinking. Were we listening? She looks toward her scar again, and she says: "*That's* where he hits me. There. When I don't have any more money."

Arthur Kleinman has written of ethnography as the study of what is at stake, an elegant and deceptively transparent formulation.[13] The stakes in the postoperative scar differ for the women in the room, for the doctors in Bangalore, for the husband who hits, and for me. For the women, the scar has two moments: a recent past when it marked their successful efforts to get out of extreme debt and support their households, and an indebted present when it has come to mark the limits of that success. A sign of the embodiment of the loans one seeks to supplement wages and give life to one's family, the scar reveals both the inevitability of one's own body serving as collateral and the limits to this "collateralization." One has only one kidney to give, but the conditions of indebtedness remain. At some point the money runs out and one needs credit again, and then the scar covers over the wound not of a gift but of a debt.

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For the doctors, the scar is the sign that nephrectomy can and does heal, given their knowledge of the operation, skills, and commitment to what they are doing. Life for life, another physician had said: the real wound is poverty and the operation provided the money to heal it. And yet there is the persistent fear, the counter-knowledge that things can and do go wrong, not only in the healing of the flesh but in the healing of the impoverishment the flesh stands for. Doctors know that sellers have little to no access to hospital care, that they often have to work at strenuous labor, that they are undernourished, and that they live in neighborhoods where infectious disease and alcohol are endemic. They know that much of the money passes quickly through the hands of sellers and goes to moneylenders and that many sellers lack bank accounts. In a different register, doctors also know the public is concerned about rumors of organ-thieving gangs, and rival hospitals might foment an accusation against one or another of them: both public anxiety and the strategies of rivals can bring the police in at any moment. No matter how good the surgery, the scar could still betray them, and sellers have to be kept out of sight.[14] Like de Sade's libertines, the doctors try to erase all evidence of the cut.

For me, there was the search for traces of a more accountable medical narrative. Also, and less credibly, there were the thrill of the chase, the elite pleasures of building theory, and perhaps the premature anxiety over new biosocial arrangements that Paul Rabinow has called "purgatorial" driving my attack on medical practice from a putatively higher ground.[15]

And for the husband? I never met him, and for all my easy if persistent repugnance I do not know how to imagine the pain of the wound he felt on another's body and the absence behind the arc of his blows.[16] One is left with an inadequate sense of the deformation of the operation's promise, and with it the scar's slow slide from a mark of positive exchange to one of persistent debt.

LIFE FOR LIFE

Contemporary debate on the ethics of the sale of organs surgically removed from the bodies of the poor is shifting. Increas-

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ingly, philosophers, physicians, and social scientists are willing to suspend concern and to consider the case for a market in human organs. In India—the most well known of what is now a large number of countries supporting an emerging market in kidneys—several prominent opponents of sales have reversed their position. One of the most vocal of these is R. R. Kishore, formerly a high-ranking medical bureaucrat and currently an active player in the multilateral conferences and task forces constituting the global expansion of the field of bioethics. An architect in the development of the 1994 Transplantation of Human Organs Act, Kishore, in a 1998 interview in Delhi with my colleague Malkeet Gupta and me, concluded that he had made a terrible mistake.

Kishore went through his reasoning carefully. Cadaveric donation will not work in our country, he said, repeating a frequently heard claim. The infrastructure is not adequate; the mentality will not support it. And even though in a few years "we will be able to grow fetuses like popcorn"—a tantalizing phrase—the use of clone technology may have its ethical limits. For the needs of our population, Kishore suggested, we have to reconsider our stance. He turned to a bit of role-playing: "Look, I'm a man dying of hunger. I ask this one for help, he does nothing. That one, nothing. Now I ask you. You say: I'm also dying. I need an organ. I'll help you if you help me." Allowing for an exchange of one man's surplus money for another man's surplus kidney is not really traffic, Kishore concluded, but "life for life." Everybody wins.

A more sophisticated version of this case for the sale of organs has been made by the British philosopher Janet Radcliffe-Richards and endorsed by her fellow members of the WHO-supported International Forum for Transplant Ethics in a 1998 article in *The Lancet*.[17] In brief, the group has made four points:

1. The standard arguments against the sale of kidneys rely less on logic than emotion, and require more to justify paternalist refusals to allow people to do as they wish with their bodies.
2. Such arguments make an exceptionalist case for the exploitation, coercion, and risk of selling organs while ignoring

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the myriad other exploitative, coercive, and risky things poor people do to survive *and will have to do more of* if organ sales are disallowed.

3. The particular forms of exploitation involved in the organ trade are in large measure due to its informality and illegality, and the best response to them may be to centralize, formalize, and legalize the trade.
4. The fact that few people with chronic renal failure are able to avail themselves of this expensive option is no indictment of the kidney trade in itself but of the nature of private medicine and, more generally, of the political economy, and responses should focus there.

The authors go on to challenge many of the communitarian, slippery-slope, and denial-of-agency arguments made by opponents of a regulated market. In a nutshell, the traffic in kidneys, if properly regulated by the state, is a win-win situation. You get a kidney, I get money, and we both therefore survive against all hope.

I wish to provide suggestions from field materials for why neither Kishore's nor the International Forum's theoretical formulations may be adequate on the ground. These formulations are not necessarily the dominant ones, either in India or in the global world of bioethical debate, but they are important because they challenge an easy paternalism. I take seriously Radcliffe-Richards's call to go beyond any a priori malfeasance of organ sales, reading her concern in line with Rabinow's criticism of an ethics of suspicion in his work on genomic debate.[18] She asks us at the least to consider the case for organ sales rather than to jump into the sort of purgatorial ethics of alarm and remorse depicted by Rabinow. Fair enough. But just as the paternalist ethicist depicted by Radcliffe-Richards presumes "nefarious goings on" *prematurely*, before the fact, so she (along with her colleagues in the *Lancet* piece) appears to make several premature counter-presumptions of recognizable terrains of agency, risk, exchange, and bureaucratic rationality.

Thus, our purgatorial paternalist is content to read the wretchedness of selling an organ in formalist terms without asking

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about relative risks and benefits for persons whose wretchedness will not disappear with the banning of such transactions. But in parallel fashion, Radcliffe-Richards's thoughtful rationalist is content to presume from scattered news clippings and equally wretched stories (for example, of a Turkish man whose sick daughter dies because he cannot sell his kidney to save her) that we can speak with some authority about risks and benefits in the emerging Kidneyvakkams of the world without sustained inquiry.

The question of authority is critical. Both the straw-man paternalist and the rationalist operate through a particular logic of deferral, what I have framed as a persistent writing before the fact. This persistence is not incidental, I would suggest, but constitutive of our writing to the extent we occupy what I will term the space of *ethical publicity*. To get at what I mean by this phrase, my argument will have three parts, which will address "ethics" as a practice more or less central to all social and human scientists of medicine under the exigencies of globalization. As such, "ethics" is an ideal type. If my argument—which in its understanding of ethics as a central feature of globalization comes out of conversation with the recent work of Rabinow—is reduced only to a disciplinary attack, then I will have failed.[19]

First, I will suggest that practices of deferral allow for the reduction of ethical analysis to a transactional frame in which all considerations outside of dyads like buyer-seller, donor-recipient, or doctor-patient are reduced to secondary processes. Alan Wertheimer's thoughtful book *Exploitation* offers an example of the value and limits of such a reduction more generally.[20] For the International Forum as for Kishore, the goal seems to be to get to a win-win scenario, achievable as a matter of life for life. Policy is to be built on an understanding of social analysis as an aggregation of individual transactions.

Second, the transactional frames—describable once questions of particular institutional forms and processes are reduced to secondary phenomena—are flexible and exportable. There is a global audience for *The Lancet*; but even before the report was published almost every Indian transplant surgeon I interviewed in Bangalore and Chennai was conversant with the

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particulars of Radcliffe-Richards's writing. Ethics must be able to travel light. Neither the purgatorial visions of religiously based ethics, nor social-scientific specificity, nor modes of critical or post-structural analysis serve the contemporary moment well: they are not ecumenical, not economical, and fail to valorize the emergent subject of globalization. Radcliffe-Richards's ethics are sensibly concerned with the small minority of Indians who can afford the cost of dialysis or transplantation. For the rest, there is no point in worrying too much about organ sales, as nothing short of massive social change would have an impact on health care anyway. As medical care and expensive biotechnology become increasingly synonymous, less eschatological options for the health care of the poor become unimaginable. Several Bangalore surgeons whose procedures, unlike those of K. C. Reddy, provided inadequate to no follow-up care to poor sellers were among the most vocal popularizers of Radcliffe-Richards's writings and of the subsequent *Lancet* report. Arguments will always be productively misread, but the point is that certain ethics travel well precisely because of the flexibility of their reductive transactional frame.[21]

Third, not only flexible but also purgatorial ethics can be mobilized to serve the exigencies of the moment. Kidney scandals have erupted in Bangalore, Delhi, and many other Indian cities on a regular basis, with doctors arrested on the grounds of tricking the poor and gullible into an unnecessary operation during which a kidney was removed. Though such events certainly may have occurred on occasion, the scandals I have studied appear to be based on trumped-up charges. Accusations are used by hospital owners and politicians in league with the police to challenge rival combines of medicine and politics: given widespread public concern across class about organ theft, kidney scandals are devastating for politics and business and therefore are an increasingly useful regulative mechanism.

What is the relation between the flexible ethics of life for life and the purgatorial ethics of nefarious goings-on? My sense is that despite their substantive opposition, these modes of engagement share at least some things, things I group under the heading of publicity. Ethics has become the dominant mode of public conversation about emergent biosocial situations.[22] I

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mean "public" conversations in the double sense that has emerged via Kant and Habermas, and their critics from Horkheimer and Adorno to Michael Warner: a conversation that not only is located *in* the public sphere but more fundamentally is constitutive *of* it.[23] I will term as "ethical publicity" the rationalization of emergent biosociality through flexible logics of win-win, logics that posit an identity ("life for life") between the life of the comparatively wealthy person in organ failure and that of the debtor pressed to sell one of her organs. As Nancy Scheper-Hughes has noted, this public is divided into bodies that can be designated patients and bodies that can be designated sellers: one is either a client of the new biosociality or a vendor to it.[24] Unlike ethical publicity and its realism, scandalous publicity—by which I include the mobilization of purgatorial ethics into public scandal—demands a single public united in opposition to a piracy that yokes together imaginary and real tissue flows.

* * *

The position of philosophical consideration—the abstract perusal of the case for organ sales—is a poor defense against one's misapplication to the extent one occupies such a position of ethical publicity. The challenges that medical anthropologists have offered to ethical publicity, though partaking (as does this essay) of the same purgatorial muck that blurs reasoned apperception, remain critical maneuvers as long as the fiction of distanced ethical consideration substitutes flexible transactions for institutional and local specificity. In particular, Arthur Kleinman's critical engagement with bioethics and Nancy Scheper-Hughes's refusal to allow us any remove from the bodies and lives of poor donors and sellers map out localized responses by ethnographers that must complement critical distance.[25]

The first problem is the dyad. Take, for example, the very real claims of sellers to be able to do as they wish with this unexpected resource. Sellers are presented within flexible ethics as having a need (for money) and a desire (to sell an organ for that money). "Yes, I would do it again." But listen further in Chennai: ". . . if I had another to give." And further: "I would

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have to." Radcliffe-Richards would question paternalist denials to the poor of their agency, an understandable move against a vanguard logic that invokes false consciousness whenever "the poor" do not tell ethnographers what they want to hear. But the question is not whether the statement "I would do it again" is coerced or alienated speech but rather what happens if one keeps listening: "I would have to." Does the opposition of agency and coercion sufficiently account for this "would have to"?

The problem with an ethical argument of this sort is the unrelenting presumption that ethics can be reduced to a primary transaction.[26] This reduction frames most relevant considerations as second-order phenomena and generates a utopian formula: *if* second-order phenomena can be controlled for, *then* an ethics is possible. But in fact the primary transaction is constituted out of the very second-order phenomena that the analyst would defer: everyday indebtedness and extraordinary debt bondage in which money passes from the patient through the donor and to the moneylender and other creditors. If one keeps listening, beyond the desire that sets the market in motion, one regains the temporal specificity lost in these transactional analyses: "I would have to. That money is gone and we are in debt." In the Tamil countryside with its kidney belts, debt is primary. But it is not only debt that constitutes the frame of the primary transaction and troubles its claim of life for life. In Chennai city, debt intersects with operability and the contingent logic of biopolitical regulation. Operable women are vehicles for debt collateral—and bear the scar. "My husband needs his strength for work, and could not work if he had the operation." "Yes, I work too."

Against what is heard, the two kinds of publicity constitute alternate public terrains. For ethical publicity, gender and debt become second-order phenomena, and ethics is restored to rational actors *pace* Adam Smith. What happens several months down the line is elided. Rational consideration appears not only removed from the purgatorial but also removed from outcomes distant *in time* from the primary transaction.

In scandalous publicity, as manifest in Indian and international media, images of male victims showing the scar from an

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involuntary nephrectomy are ubiquitous. These are not the bodies of rumor: an operation has occurred, perhaps involving some measure of coercion. But the point here is that the public scar is almost always male: men offer the paradigmatic surfaces bearing scars that in urban areas cover operations on female bodies. Scandalous publicity reconstitutes the "Emergency."

* * *

How do we steer between a flexible ethics that reduces reality to dyadic transactions and a purgatorial ethics that collapses real and imaginary exploitation in the service of complex interests? I am in the midst of a four-year study in Chennai, Bangalore, Delhi, and Mumbai (Bombay), and in lieu of a full answer I offer six points as part of a work in progress.

1. *No data exists on the long-term effects of nephrectomy to sellers or families.*

Many surgeons in these four cities reported an absence of long-term effects and then went on to insist that follow-up research was impossible since they have no way of knowing where the itinerant or illiterate sellers have gone. Yet the ability of activist physicians, fact-finding teams of ethicists, and journalists to locate sellers suggests that epidemiological research on such long-term effects is eminently possible and would seem to predicate any future calculations of risk-benefit ratios.

After Reddy, two of the most internationally prominent physicians who are advocates for organ sales are Drs. S. Sundar and A. K. Huilgol of the Karnataka Nephrology and Transplantation Institute (KANTI), housed in Bangalore's Lakeside Hospital. All physicians in Bangalore and Chennai acknowledged the high standard of care KANTI offers: medically, it is an exemplary site. Like Reddy, Sundar and Huilgol make no secret of their commitment to organ sales as a win-win scenario in the context of local conditions. Like Reddy, they are carefully acquainted with Radcliffe-Richards's work and cite it to challenge opposing positions as both intellectually unsustainable and naïve. Unlike Reddy, however, Sundar, in several

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1998 interviews, deflected my question each time I asked about meeting his former sellers. When pressed, he pleaded the impossibility of finding these people or learning much from them.

Many of the Bangalore sellers have come from the Salem–Erode kidney belt. According to social workers and small-town reporters working in that region, these sellers are primarily men who left unirrigated "dry" farming districts for the promise of steady work as the power-loom industry dispersed from cities like Chennai to cheaper production sites. Unlike the Ayanavaram and Villivakkam sellers, these men are more likely to be recent migrants who are indeed harder to follow. This difficulty has been used to forestall attempts to generate data.

Part of Sundar's cautiousness may arise from the possibility of KANTI's knowing or unknowing involvement in the trade. Sundar denies awareness of any illegalities: if his patients say the donor is a relative or family friend, and if the state authorization committee has concurred when necessary, it would be wrong, he argues, not to go ahead. Sundar is open about patients who seek out the committee. KANTI in fact makes a public display of its transparency. The waiting room is lined with large wall charts listing the numbers of every procedure carried out by KANTI and its sister clinics in the state. News clippings attesting to KANTI's popularity in Bangladesh are hung along with a computer-generated sign from Bangladeshi patients thanking the clinic.

Despite this transparent design, three members of the Karnataka State authorization committee who were interviewed acknowledged that few of the donors they were asked to consider were relations or friends, from KANTI or most other Bangalore clinics. Why do committee members approve these donors, then? The state secretary who runs the committee said in an interview with me that patients and physicians have political allies who pressure the committee to grant approvals. Reddy is but the most prominent of several transplant doctors who specifically accused Sundar and Huilgol of "going too far" in turning transplants into big business. Reddy claimed that KANTI has advertised in Sri Lanka and Bangladesh for patients and that Sundar and Huilgol had come to the Kidneyvakkams of Chennai in search of sellers. Part of Reddy's concern might

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have been territorial: the urban Kidneyvakkams had for several years supplied Chennai clinics, while the rural kidney belts to the west had supplied Bangalore. "They have become greedy," he said—suggesting that, far from being unable to determine the provenance of kidneys, Sundar and Huilgol themselves served as procurers.

Sundar and Huilgol may well be the victims of false accusations by competitors. But their resistance to follow-up research is striking. The only things missing from the prodigious display of data shown by KANTI on its walls, in its publications, on its web site, and through its dealings with the press are the bodies and statistics of donors. The second time I tried to get Dr. Sundar to talk about a possible follow-up study of donors he took out a copy of a Radcliffe-Richards article from his desk and asked me if I had read her. He read choice phrases of the article to me, dismissing my concerns over sellers as paternalist. But where were the donors? If the market structure of transplantation deflects attention from the actual bodies of sellers onto ideologically constituted proxies, how complicit are flexible ethics in maintaining postoperative inattention to sellers?

2. *Decisions to sell a kidney appear to have less to do with raising cash toward some current or future goal than with paying off a high-interest debt to local moneylenders. Sellers are frequently back in debt within several years.*

The Ayanavaram slum dwellers who sold their kidneys described their reasons for selling and their desire to sell again if biologically possible in terms of a transaction not with the present or future—an operation to pay for, a house to buy, a shop to set up, a wedding to finance—but with the past. They were in debt, and could no longer manage their indebtedness and still feed and shelter a household. This finding is tentative, for as most of these borrowing and lending transactions are through private moneylenders and small shopkeepers as opposed to state or private banks or credit associations, data to confirm sellers' and nonsellers' patterns of indebtedness are difficult to generate. But the testaments of sellers do correlate with the work of investigative journalists in Chennai.[27] Furthermore, they make sense within the topography of credit in poor

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Chennai neighborhoods, in which moneylenders and pawnbrokers are ubiquitous.

None of the Chennai sellers interviewed claimed to have a bank account, and they offered the usual reasons: they were illiterate or poorly literate and of low status, and therefore could not negotiate the language and status practices of the bank bureaucracy with any certainty. Stories of money lost to bankers were common. Jewelry offered a seemingly more practical locus for saving, though stories of gold stolen or appropriated were not uncommon. Most of the kidney money went to pay off debt, and the expenses of husbands and children—education, marriage, medical costs, legal fees—took the rest. Several of the women interviewed mentioned men who drank up the savings.

Persons sell a kidney to get out of debt, but the conditions of indebtedness do not disappear. All of the thirty Chennai sellers with whom Coutinho and I spoke were back in debt again. Organs and blood, from the perspective of the debt broker, are but two of the multiple sites of the collateralization of the poor, ranging from patterns of debt peonage with lengthy pedigrees to expanding new markets in children for adoption, labor, and sex work. Technological transformation like that mediated by the emergence of cyclosporine offers new biosocial strategies for debt markets seeking under the logic of capital to expand.

The argument here is that the decision to sell may be set for debtors by their lenders, who advance money through an embodied calculus of collateral value. In other words, the aggressiveness with which moneylenders call in debts may correlate with whether a debtor lives in an area that has become a kidney zone. If so, the decision whether or not to sell is a response not simply to some naturalized state of poverty but to a debt crisis that might not have happened if the option to sell were not present. Based upon these interviews and discussions with historians, social workers, and journalists in Chennai, my hypothesis is that kidney zones—the vakkams and belts of Tamil Nadu—emerge through interactions between surgical entrepreneurs, persons facing extraordinary debt, and medical brokers. As a region becomes known to brokers as a kidney zone, their search for new sellers intensifies. Persons in debt are approached.

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In urban areas, more women than men respond. Creditors, who must advance and call in loans with an eye to interest, collateral, and reproduction—that is, to how much of the debtors' resources to take while keeping them alive and healthy enough to be able to make future payments and take out more debt—also respond to these shifting circumstances.

Debtors' recounting of the process of debt supports such a process, as does my informal observation of moneylenders and discussions with Chennai and rural Tamil Nadu journalists and social workers who cover questions of credit and debt. More analysis of local credit practices is needed.

3. *Few persons in India can afford the cost of transplantation or dialysis, so whether or not organ sales are legalized the majority of persons with end-stage renal disease will die. Programs to prevent end-stage renal disease are few, and prevention is not part of the dominant European or American conversations on organ sales, whether pro or con.*

The first part of this finding is a commonplace. Radcliffe-Richards and her colleagues accept it but argue that the question of the poor's access to medical care is irreducible to their access to transplant surgery. Purgatorial anxiety over organs is a self-serving substitute for concern over universal health care.

Again, at an imagined distance this logical maneuver makes sense. But reformulated in terms of ethical publicity, it deforms in a predictable fashion. At KANTI, when I asked Sundar how he could support a market in kidneys given no data on the risks to Indian sellers, he, like Reddy and most other transplant physicians interviewed, responded that when a person dying from poverty comes to your door and asks why you will not help him, the situation requires action. The scenario of a request from a dying person is disconcerting and problematic, for the vast majority of persons living with and dying from renal disease could not and would not be attended to, as they lack the funds for dialysis or transplantation. Yet the sellers fulfill the terms of the ethical scenario as set by these doctors: a dying person asks you for help—what do you do? Somehow, such a scenario does not trouble these physicians in the way the suffering of the more well-to-do appears to.

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When I asked the KANTI team about this apparent inconsistency, they smiled indulgently. We are a poor country, Sundar reminded me, and as much as it would improve my business to have the government pay for transplantation for the majority of Indians, I do not think it can be a priority for us. Government money needs to go to primary care.

The move is impressive, and dizzying. Sundar, and the majority of transplant doctors who concur with him, are masters of ethical publicity. There is no need to worry about health risks to the poor seller, because a physician must always worry about the individual patient: his or her ethical compact is with the individual sufferer. Yet there is no need to worry about the majority of individual sufferers, because an Indian physician must always think on the societal level, where the money would be better spent on inoculations. What is alarming is the sleight of hand by which individualist and communitarian rationales for a medical ethics replace each other in turn to justify business as usual.

In this context, the inattention to questions of prevention, to renal medicine that in the long term might be both affordable and effective for "a poor country," is particularly significant. Communitarian logic serves only to justify inattention and to slough off poor patients to public hospitals. Transplant physicians, despite their immersion in bioethics and communitarian appeals, are with notable exceptions not involved in campaigns of public education or the development of low-cost alternatives to current dialysis. Their persistent resistance to cadaveric donation, which would provide an alternative to the use of the organs of the poor, is troubling. Most surgeons interviewed cited India's "infrastructure" or "mentality" as problems, but several pioneering cadaveric programs in the country are emerging, and their founders argue that the single most significant impediment to success is the unwillingness of most private transplant clinics to participate. Reliance on cadavers cuts down on a ready supply of organs and diminishes profits. In Bangalore, John and Rebecca Thomas—trained in Pittsburgh, the Mecca of transplant surgery—launched an effort to build an equivalent to the United Network for Organ Sharing (UNOS), a distribution and information network linking brain-dead cadavers to persons on a waiting list. Their efforts, though pub-

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licly applauded, have been met with significant resistance. No hospital wants to give away its own cadavers to a pooled list. Both brain-death transplantation and lists are far from perfect alternatives to sales, as the work of Margaret Lock on the former and Scheper-Hughes on the latter have shown.[28] But debate on cadavers has not focused on the medical and ethical limits of brain death as a viable concept. Rather, lip service under a rhetoric of development is paid to ever-deferred infrastructural and institutional possibilities.

4. *Buyers of kidneys often underestimate the risks and long-term costs of immunosuppressive therapy, leading to dose tapering and organ rejection after catastrophic expenditure.*

Buyers no less than sellers are at risk. Scheper-Hughes has documented the predicament of poor organ recipients in Brazil who cannot afford to maintain cyclosporine immunosuppressant therapy and so taper or pool doses. Members of the Bangalore Kidney Patients' Welfare Association, which meets once a month in a city park to distribute low-cost immunosuppressant therapy (but not the most expensive and most necessary drug, cyclosporine), offer similar stories of middle- and working-class persons who utilize networks—relatives, job benefits, insurance, and statewide "governor's funds" set up for medical emergencies—to raise the cash for the operation, for the organ in the case of sales, and for the medication. These organ recipients anticipated one to three years of diminishing immunosuppressant therapy, and thus either were not anticipating the long-term costs adequately or simply did not realize that therapy might last for many more years. A monthly dose of cyclosporine costs more money than many of these families bring in each month as income. Further ethnographic work is needed to study the preoperative interactions between patients and doctors to understand what message about long-term costs patients are receiving and how they interpret it over time.

Part of the problem is that younger nephrologists are less aggressive in how many tissue factor "matches" there need to be between donor and recipient kidneys in order to go ahead with the operation. Cyclosporine, in combination with other drugs, makes a transplantation with fewer matches medically

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viable in certain patients. With the predominance of transplants of kidneys from nonrelatives (now disguised under the terms of the 1994 act), requiring fewer matches means one is more likely to find available sellers and conduct more procedures. I have witnessed debates between older and younger physicians over the appropriate number of matches. As the number of matches comes to be seen as less important, the length of time patients will remain on cyclosporine increases. Patients and physicians reported one to three years as a ballpark figure to me, but the figure may be based on data from a different climate of tissue typing and matching.

Novartis, the maker of cyclosporine, is ubiquitous in the global transplant world and in India. It funds many conferences, not only on organs but on medical ethics more generally, and its representatives attend public gatherings like those of the Welfare Association. At one such meeting, one recipient's father literally begged the drug representative for a free month's supply of the drug as he had no credit left. The drug was provided, and apparently this exchange was a repeated scene. Novartis becomes the great benefactor for this organization of recipients, and no actions to lower the price are proposed.

5. In major urban centers, the growing number of transplant programs led to intensified competition in the mid-1990s for recipients who could afford the cost: the ethics of transplantation in India are driven less by a shortage of donors than by market demands given a shortage of recipients.

KANTI is one of eight transplant centers that was established in Bangalore within a decade, in a state where dialysis is almost nonexistent. This rapid expansion was in part a function of demand, though the supply of persons who could afford the triple cost of operation, organ, and drugs was quickly exhausted. Beyond demand, a transplantation ward advertises a new or competitive private hospital as modern and well-equipped: this reputation may be profitable beyond the income generated by the ward itself. Transplantation signifies (marketable) modernity.

As the supply of persons who could afford the operation diminished, competition between these many programs intensified, and directors began looking for new markets. With the

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passage of the 1994 act, the number of foreign recipients—typically from the Persian Gulf region, Europe, and Asia—went down sharply. Hospitals were worried about scandals, and it was harder to pass off a local donor as a friend or relation of a foreigner. Clinics like KANTI looked to both Sri Lanka and Bangladesh, where recipients without relatives could bring their own donors or sellers. With the number of applicants for kidneys in decline, it is possible that middle- and working-class households who could afford the operation but not the immunosuppression were more aggressively approached. This impression is the one offered by Welfare Association members, but further study is needed.

If clinics face less a shortage in organs than a shortage in persons wealthy enough to take them, they need to organize their practice around a manageable and relatively low-cost source of human material. Recipients can go elsewhere, and one must have potential kidneys ready. The business of these clinics depends on the market, and would be made far more risky with a turn to cadaveric donation.

The point here runs against the continual language of *shortage* that some ethicists take for granted. Putting aside the vexed issue of whether one can even speak of a shortage of people's organs—an issue drawing on a philosophical analysis of property extending from Locke to Marx and seldom engaged within the ethical literature under consideration here—one must ask whether the critical shortage is not of donors but of *recipients*. The practices and the ethics we need to consider are rooted in the economics of this latter shortage.

6. *The rapid growth of transplant medicine in the 1990s was part of a larger period of medical institution-building in India in which high-end, privatized medical care became a major site of investment and foreign monetary exchange, and new public-private assemblages emerged linking medical institutions and political influence to various sources of capital—liquor, armaments, pharmaceuticals, and "black money."*

Transplant medicine, as a continual goad to public and foreign anxiety, became a strategic site for intervention within and

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between competing assemblages. The frequent manufacture of scandals in which doctors are accused and jailed as kidney thieves appears to be one such intervention.

One must differentiate kidney panics from kidney scandals. In panics, stories of missing or murdered children circulate and become tied to fears over kidney thieves and to the legitimation of state and international involvement. The stories are often based on real disappearances and child loss in the contexts of malnutrition and hunger, of debt bondage and child labor. State agencies are challenged or attacked, and state responses focus upon denying the stories and providing the materials for renarrativization.[29]

Scandals are not threats to state order but forms of publicity collaboratively produced by a mix of state and nongovernmental agencies. The police arrest a group of doctors and the media are notified. Emerging accounts are framed not as positings of hidden gangs and state conspiracies but as stories of greed and corruption. Brokers and doctors collude in tricking people into having medical tests with the promise of a job; people wake up with a scar. Such scandals have taken place in Bombay (not yet Mumbai) in 1993, Bangalore in 1994, Jaipur in 1996, and the Delhi suburb of Noida in 1998. Most of these trials are still pending.

It is, of course, possible that the physicians accused are guilty of all charges. Scheper-Hughes has carefully documented organ theft worldwide, even though she began her research to show the opposite: that these stories were symptoms of histories of poverty and state violence but not necessarily "real" thefts. Certainly worse examples of medical malfeasance occur daily. Yet one must exercise caution. With a large and growing number of persons in debt crises there would seem to be no immediate shortage of sellers, and it is not clear why clinics would take the high risk of cheating someone. Then again, police can be easily bought off, and the victims in most of the scandals (but not all) were socially marginal and unlikely to be heard. At present, one must defer final judgment.

Why, though, in each of these cases do the police act with such speed on the claims of poor and socially marginal accusers? In Noida, a senior superintendent of the police with a

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medical background was specifically transferred in to monitor the case. The accused physicians have mobilized their political connections in an effort to be released, but according to several state medical officials who spoke with me on the grounds of anonymity, the word has come down from the chief minister's office that the case is not to be touched.

The earlier Bangalore scandal was similarly surrounded by hearsay. The Yellamma Dasappa Hospital, where the scandal was centered, is owned by an industrial group that was competing with another industrial group for a lucrative state contract to supply cheap liquor. (Most of the city's hospitals are owned by large industrial concerns, several by liquor companies.) Several hospital administrators, social workers, and journalists suggested that the contract negotiations lay behind the manufactured scandal. The police denied this.

"Manufactured" is deceptive here. If most transplant clinics have violated the letter and spirit of the Indian Penal Code and the later 1994 act in using sellers or passing them off as family or friends, and if sellers are provided minimal care and shunted back to the villages or slums, most clinics are therefore vulnerable to accusation—thus KANTI's strategy of performative transparency. But why police involvement? Most new clinics and hospitals have had to rely upon extensive political patronage to wade through regulations designed to promote a public health sector and limit private growth. Available urban land often has squatter colonies, and significant political capital is needed to move a potential "vote bank." Conversely, the new hospitals offer a variety of services to politicians and industrialists, ranging from a source of political patronage to a literal tax shelter where industrialists and others under trial for foreign exchange and tax violations can be admitted to defer a court date in perpetuity. Journalists and other cosmopolitans in each of the aforementioned cities where kidney scandals continue offered dozens of accounts of the nexus between the new medicine, politics, and industry—some substantiated, many not.

Transplantation, both because it is a critical site of publicity around which periodic panics emerge and because it often involves a nested series of illegalities and produces a class of potentially exploited persons, seems to have become a key node

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around which competition for control of medical, industrial, and political resources is negotiated. The paradox is therefore created of a politics that tries to quell kidney panics while abetting the periodic negotiation of scandals.

What is the relevance of these scandals to the sociology and ethics of the market in organs? First, they push us to take seriously the need for an ethnography of the state. Radcliffe-Richards and her colleagues make a classic transparency argument, parallel to those used to defeat prohibition or decriminalize prostitution and drugs: if there is exploitation, then legalizing and regulating the market cleans it up while allowing sellers their autonomy. But this argument presumes a state structure, one in which increased regulation has a specified effect and the organization of the state can address the organization of the market. But what if the organization of the trade *mirrors* the organization of the Indian state in its need for brokers? The presumption of the ethicists seems to be that once India is developed into a certain assemblage of rational bureaucratic forms, the current abuses will disappear. This presumption imposes a narrative of the development of the state with little empirical grounding. In consideration of the recent work of Akhil Gupta on the ethnography of the Indian state as well as the writing of Veena Das, Ravi Rajan, and others on the bureaucratic management of treatment for the Bhopal gas disaster victims, what seems more likely is that any new central bioauthority will generate a new class of agents demanding payments from sellers.[30] Such "bioethical brokers" may supplement, rather than eradicate, currently existing tissue brokers and debt brokers in the lives of the poor. At any rate, these are empirical questions that require ongoing ethnography before distanced consideration can be achieved.

CODA: OTHER ETHICS

Neither Kishore, Reddy, and Sundar nor the agents of public scandal currently hold the field in India, although things change fast. Medical activist organizations like the Voluntary Health Association of India (VHAI) still attract multilateral fiscal support and steer a course between acknowledging some nefarious

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goings-on and passing over transplantation to arrive at more urgent questions of infections, environmental degradation, and access to primary health and hospital care. The dominant formation in Indian bioethics is purgatorial, but with a somewhat different lineage from the ethics challenged by Rabinow. Missionary discourse and aesthetics predominate, and the message of a new science stressing care against commerce and love against paternalist medicine offers the reclamation of society against a sense of loss experienced and inscribed as colonial. Such missionary ethics form another public space, one that travels well along certain routes. At the Fourth World Congress of Bioethics in Tokyo, Japan, in 1998, one of the dominant presences was Darryl R. J. Macer, the author of *Bioethics is Love of Life: An Alternative Textbook*.[31] Macer challenged most professional ethical stances, but in his repeated "All you need is love" theme what really fell out of the equation was politics. Against flexible ethics, Macer and his followers downplayed any VHAI-type response and set up a global mission, a secretariat of love.

But if the only alternatives to a world split between clients and vendors are reconstitutions of Christian love, the result seems to be that vendors are authorized to define themselves through the gift, with clients remaining the beneficiaries. In Bangalore and Delhi I was told stories of persons possessed by a kind of donation madness: a man desperate to give away any organ he could; a couple who insisted all their wedding guests sign up to donate something. But in conversations with recipients, I continue to hear love in a different sense: *Why should I put a family member I care about at risk by asking him or her to donate an organ when I can just buy one?*

* * *

The production of scandal, through sociologically complex linkages of state and market agencies and old and new media, maintains the image of a distinctive state apparatus that can intervene to regulate medical abuses against the poor. This image is central to ethical publicity, justifying its presumption of a universal and liberal state structure allowing the invisible hands of utility and

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reason to guide an individualist ethics of radical autonomy. The public productions of such an ethics are consumed and elaborated by transplant professionals and more generally by the corporate/political hybrid of contemporary health care.

To what world do such ethics speak? Midway through this research, we are left with scattered signs: a woman offering both of her kidneys to MGR; a man in a park begging to a Novartis representative; a postoperative complication of a painful scar that began to hurt when the money ran out.

ACKNOWLEDGMENTS

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ENDNOTES

[1]George Marcus has written several well-known essays on the risks and benefits of anthropology spreading itself thin, collected in *Ethnography through Thick and Thin* (Princeton: Princeton University Press, 1998).

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[2]Patricia A. Marshall, "Organ Transplantation: Defining the Boundaries of Personhood, Equity and Community," *Theoretical Medicine* 17 (1) (1996): R5-R8; Patricia A. Marshall and Abdullah S. Daar, "Cultural and Psychological Dimensions of Human Organ Transplantation," *Annals of Transplantation* 3 (2) (1998): 7–11.

[3]"Kidneys Still for Sale," *Frontline* 14 (25) (23–26 December 1997); "Options before Kidney Patients," ibid.; "For a Cadaveric Transplant Programme," ibid.

[4]Raj Chengappa, "The Great Organs Bazaar," *India Today,* 31 July 1990, 60–67.

[5]Interviews were recorded and are being transcribed. This summary comes from my written notes taken at the time of the interviews and checked against the tapes; it represents what was common to most interviews and is not verbatim.

[6]The history of the medicalization of the south in the *longue durée* has not been attempted, with the partial exception of a long-standing debate over the exemplary status of the neighboring state of Kerala. In what is now Tamil Nadu, such a history may extend from Chola-dynasty urbanization to the nineteenth-century emergence of large networks of medical missions and to their influence on the norms and forms through which Tamil and Telegu elites constituted the public space of Madras. I thank Eugene Irschick and Shiv Visvanathan for conversations helping me to sketch out the contours of an imaginable history.

[7]Cecilia Coale Van Hollen, "Birthing on the Threshold: Childbirth and Modernity among Lower Class Women in Tamil Nadu, South India," Ph.D. dissertation, Department of Anthropology, University of California at Berkeley, 1998; and "Moving Targets: Routine IUD Insertion in Maternity Wards in Tamil Nadu, India," *Reproductive Health Matters* 6 (11) (1998): 98–106.

[8]Patricia Jeffery, Roger Jeffery, and Andrew Lyon, *Labour Pains and Labour Power: Women and Childbearing in India* (London: Zed Books, 1989); Van Hollen, "Birthing on the Threshold."

[9]The link of operative loss to citizenship has multiple referents in India. Perhaps the most illustrative is the case of castrated *hijra*s ("eunuchs"), who claim to lift their saris and show the absence produced by an operation in order to travel on trains and buses and even to cross borders into Bangladesh: the absence is the *hijra*s' "all-India pass" or "passport."

[10]Van Hollen, "Birthing on the Threshold."

[11]See Gilbert H. Herdt, *Guardians of the Flutes: Idioms of Masculinity* (New York: McGraw-Hill, 1981) and Klaus Theweleit, *Male Fantasies* (Minneapolis: University of Minnesota Press, 1987–1989).

[12]Van Hollen, "Birthing on the Threshold."

[13]Arthur Kleinman, *Writing at the Margin: Discourse between Anthropology and Medicine* (Berkeley: University of California Press, 1995), 98–99.

[14]The aforementioned Dr. Reddy, here as elsewhere, is the exception. Unlike transplant physicians interviewed in Mumbai, Bangalore, and Delhi, Reddy made it very easy to locate his sellers.

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[15]Paul Rabinow, *French DNA: Trouble in Purgatory* (Chicago: University of Chicago Press, 1999).

[16]See Veena Das, "Wittgenstein and Anthropology," *Annual Review of Anthropology* (1998). Das offers Wittgenstein's figure of feeling pain in another's body to frame the possibilities and consequences of an anthropology of suffering. Here this figure is extended and inverted.

[17]Janet Radcliffe-Richards, "Nephrarious Goings On: Kidney Sales and Moral Arguments," *Journal of Medicine and Philosophy* 21 (4) (August 1996): 375–416. Janet Radcliffe-Richards et al., "The Case for Allowing Kidney Sales," *Lancet* 351 (9120) (27 June 1998): 1950–1952.

[18]Radcliffe-Richards, "Nephararious Goings On"; Rabinow, *French DNA*.

[19]See Gísli Pálsson and Paul Rabinow, "Iceland: The Case of a National Human Genome Project," *Anthropology Today* 15 (5) (October 1999): 14–18.

[20]Alan Wertheimer, *Exploitation* (Princeton: Princeton University Press, 1996).

[21]I use "flexibility" mindful of Emily Martin's adaptation of the social and economic uses of the term to the study of bodily experience, politics, and research first done by David Harvey. See Emily Martin, *Flexible Bodies: Tracking Immunity in American Culture from the Days of Polio to the Age of AIDS* (Boston: Beacon Press, 1994); and David Harvey, *The Condition of Postmodernity: An Enquiry into the Origins of Cultural Change* (Oxford: Blackwell, 1989).

[22]The concept of the "biosocial" was developed by Rabinow through the Foucauldian concept of biopolitics as a way to address critical linkages between biology and society other than the adaptationist reduction of sociobiology. See Paul Rabinow, *Essays on the Anthropology of Reason* (Princeton: Princeton University Press, 1996).

[23]On Kant, see James Schmidt, ed., *What is Enlightenment?: Eighteenth-Century Answers and Twentieth-Century Questions* (Berkeley: University of California Press, 1996). On the Frankfort School, see Craig Calhoun, ed., *Habermas and the Public Sphere* (Cambridge, Mass.: MIT Press, 1992).

[24]Nancy Scheper-Hughes, "Theft of Life: The Globalization of Organ Stealing Rumours," *Anthropology Today* 12 (3) (1996): 3–11.

[25]Kleinman, *Writing at the Margin*; Scheper-Hughes, "Theft of Life."

[26] Nancy Scheper-Hughes has been making a similar point in her current work on organ transactions in Brazil and South Africa.

[27]"Kidneys Still for Sale," *Frontline* 14 (25) (23–26 December 1997). This *Frontline* piece includes interviews with rural male sellers:

> Subhash ran up a debt of Rs.35,000 after the tea shop he owned caught fire; Govindan, a powerloom worker, borrowed Rs.45,000 when his daughter was married. With their creditors pressing them to pay up and nowhere to go, each decided—not without reluctance and a feeling that it would all come to no good—to sell an asset he did still possess, a kidney. . . . Govindan received the promised amount of Rs.35,000 while Subhash received Rs.30,000, one-third less than he was promised. They

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paid back a part of their debt but began to borrow heavily once again. They were weak and unable to work as earlier. Neither has visited a doctor since the surgery. Subhash is already in debt to the tune of Rs.25,000, Govindan of Rs.10,000.

[28]Margaret Lock, *Twice Dead: Circulation of Body Parts and Remembrance of Persons* (Berkeley: University of California Press, forthcoming); Nancy Scheper-Hughes, personal communication.

[29]I have written about one such panic, in the city of Varanasi and its hinterland in 1996. Lawrence Cohen, *No Aging in India: Alzheimer's, The Bad Family, and Other Modern Things* (Berkeley: University of California Press, 1998).

[30]Akhil Gupta, "Blurred Boundaries: The Discourse of Corruption, the Culture of Politics, and the Imagined State," *American Ethnologist* 22 (2) (1995): 375–402; Veena Das, *Critical Events: An Anthropological Perspective on Contemporary India* (Delhi: Oxford University Press, 1995); S. Ravi Rajan, personal communication.

[31]Darryl R. J. Macer, *Bioethics is Love of Life: An Alternative Textbook* (Christchurch, New Zealand: Eubios Ethics Institute, 1998).

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It is striking that the culture and values of the "West" are scrutinized in the brain death debate in Japan. We hear and read much about Christianity (but nothing of Judaism), about rationality and the brain as the center of the body, about altruism, individualism, and even selfishness—all values associated with the "West." But, despite a call to move beyond a discussion of scientific decision-making, as noted above, Japanese values are not often examined explicitly. It has been suggested by some that if the original heart transplant, the Wada case, had not flared up into a legal battle, the entire brain death debate may never have surfaced, and the medical world would simply have gone ahead unilaterally as they did in North America. Others strongly disagree with this position, although many believe that brain death will be made legally acceptable in Japan fairly soon and that the search for a national consensus is simply a placatory exercise before those in power go ahead to institutionalize organ transplants; indeed, a private members bill has recently been submitted for consideration to the Diet.

Thoughtful people recognize that while brain death is obviously a sensitive topic, the definition of death, although clearly the nub of the debate, has a metaphorical significance that triggers a cascade of ideological repercussions reaching far beyond the medical world. The present dilemma for progressive thinkers in Japan is how to dispose of the remnants of patriarchal and patronage thinking—the reactionary part of the Confucian heritage—without drawing on a language that single-mindedly pursues the entrenchment of the "Western" values of individual autonomy and rights. It is in this context that the argument about brain death is taking place, and, as in the West, it is an overwhelmingly secular argument in which representatives of religious organizations are, for the most part, remarkably absent.

Margaret Lock

From "Displacing Suffering: The Reconstruction of Death in North America and Japan"
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Mary-Jo DelVecchio Good
with Esther Mwaikambo, Erastus Amayo,
and James M'Imunya Machoki

Clinical Realities and Moral Dilemmas: Contrasting Perspectives from Academic Medicine in Kenya, Tanzania, and America

INTRODUCTION

PHYSICIANS IN UNIVERSITY HOSPITALS in Africa face a fundamental moral crisis: hospitals are overwhelmed by patients dying from AIDS, and physicians have few resources to respond. In such settings, not only do physicians face very specific moral dilemmas—how to ration scarce resources and acquire costly medications, how to inform families that a child is HIV positive—but the very moral foundations of medicine as a scientific and caring profession are called into question. Practicing medicine and training new physicians in such settings produce profound ethical dilemmas.

On the surface, the situation in teaching hospitals in North America could hardly be more different. Resources for high-technology medical practice are abundant, though not unlimited. Physicians and medical students see a wide range of dis-

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ease conditions and manage patients with diverse prognoses. Ethical dilemmas about when to provide or withhold care and how to involve patients in decision making are present, but at a different level.

This essay examines the moral dimensions of medical practice in these two very different "local moral worlds," acknowledging that both belong to the *same* world and the *same* moment in time. African and American physicians belong to the same profession. Their training is similar, they read the same medical journals, they have similar values, and African physicians practice with an awareness that resources for treating conditions such as HIV/AIDS are readily available in much of the world. What, then, can be learned about the moral dimensions of medical practice by examining these two very diverse—but contemporaneous—moral worlds side by side? In what way do ethical issues of medical practice vary in these different settings? Are there similarities, even universals, that crosscut them? What are the moral implications for medicine and doctors in North America of recognizing the dilemmas facing their physician colleagues in Africa?

In an essay in *Writing at the Margin,* Arthur Kleinman makes two critical observations that capture the encounter of anthropologists with bioethics. First, he argues that "if there is to be any approach in bioethics that engages culture, surely it needs to be one that deals with clinical realities, and to do so it must be anthropologically informed."[1] Second, he urges anthropologists and medical ethicists to distinguish between the "ethical" and the "moral," the "codified body of abstract knowledge held by experts about 'the good' and ways to realize it . . . and moral commitments of social participants in a local world about what is at stake in everyday experience. Both are cultural processes but of a different kind. . . ."[2] Kleinman's observations suggest that we ask what is "local" about "local moral worlds," and how the moral articulates with the ethical. What gives universality to moral dilemmas encountered in daily medical practice in settings as diverse as East Africa and North America? How do tensions between local and universal standards, expectations of professional competence, and distinctive social and cultural settings shape the moral discourses of medicine's mul-

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tiple voices and produce multiple "regimes of truth"? What crosscuts the local and the universal? And what are the conceptual and practical pitfalls in an anthropological defense of "local moral worlds," especially when used in the domain of contemporary professional medicine?

I examine these issues by reflecting on illustrative data from research in two distinct medical settings. The first example emerges from an ongoing collaboration with my physician colleagues and former fellows from Tanzania and Kenya (Drs. Esther Mwaikambo, James M'Imunya Machoki, and Erastus Amayo). The project centers on the impact of economic scarcity and disease entities (in particular HIV) on medical culture, training, and education, and on patient care in these two countries. Our inquiry began with informal conversations that led to formal interviews and, most recently, pilot investigations with faculty physicians, residents, and medical students in Kenya and Tanzania.

The second example draws on my decade-long research on high-technology medicine and the culture and political economy of oncology as practiced in American academic medical settings.[3] My collaborators, Drs. Rita Linggood and Irene Kuter, are clinician-scientists who exemplify the wedding of clinical science and patient care. Data are drawn from interviews and ongoing conversations with oncologists that I have been carrying out over the past decade, from documents from the professional world of oncology, and from our formal study of clinical narratives in oncology—including formal interviews with, and recorded interactions over the course of treatment between, physicians and their patients. For the American case, we focus on BMT: bone marrow transplant treatments for advanced stages of cancer.

MORAL DILEMMAS OF AN AFRICAN KIND: "OVERWHELMED BY DISEASE ENTITY" IN KENYA AND TANZANIA

"And death no longer becomes a serious affair. . . ."

I asked Dr. Amayo, a neurologist and senior attending physician in the department of medicine in the Kenyatta National

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Hospital, the teaching hospital of the University of Nairobi, to reflect on how practicing medicine in contexts of scarce economic resources and poverty influences the culture of medical competence and standards of care. His voice was quiet as he answered, and yet his characterization of the HIV plague was shattering.

> I thought about your question in the context of my own personal experience, and in the experience of others, of medical cadres, and the change, the whole change in the disease patterns [in the past five years].
>
> Not only is there scarcity, but the essence of the . . . the principle of [doctoring] is to save life. So it comes to it that lives are no longer being saved. You have people dying much more than they used to and I really do not know how it affects me, because personally it goes to an extent where—you don't get so bothered that you had a ward which was just full, because sometimes you have wards that are really full, and then at the end of the week it's been reduced, and most are due to people who have died, and death no longer becomes a very serious affair. Before, you would get worried when one of your patients died, but now it seems to be a usual thing.
>
> When AIDS comes in, death becomes . . . even when someone has another problem, it's so encompassed in the AIDS deaths so that death looks the same. Even sometimes deaths you used to get so worried about—for example a young person dying—it is no longer having that amount of impact.
>
> And of course there is scarcity that you talk about—but scarcity in the context of whether you can do something [is different from this]. Even if I gave you everything, how much of a difference would it really make? People come, and they are just dying. It is just impossible to try to comprehend what to do.[4]

As Kenya and Tanzania struggle with "structural adjustment," dictated by the world's financial and loan markets, the International Monetary Fund and the World Bank, and with consequent reductions in contributions from the public sector for health care, medicine as a profession is reeling from a challenge of a different magnitude. A remarkable shift in the problems facing physicians began when the first AIDS case in Kenya was diagnosed and reported in 1984 by A. O. Obel and his colleagues.[5] Current figures put in context what Dr. Amayo

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means when he says physicians are "overwhelmed by disease entity." In 1998, the World Health Organization/Joint United Nations Programme on HIV/AIDS (WHO/UNAIDS) estimated that the overall HIV adult prevalence rate in Kenya was 11.6 percent; 1.6 million people were estimated to be infected with HIV Type I, out of a total population of approximately 30 million.[6] In the fall of 1996, one of our colleagues estimated that approximately 60 percent of patients in the medicine wards at Kenyatta National Hospital were HIV positive. Similar figures were given for Tanzania's major teaching hospital, Muhimbili Medical Center.

Statistics compiled in a systematic study of government hospitals in Kenya indicated that 50 percent of all patients admitted to medicine wards suffered from HIV/AIDS-related diseases; estimates of HIV prevalence among medical-ward patients at Kenyatta National Hospital for 1999 are similar.[7] In April of 1999, Machoki and his colleagues estimated that obstetrical patients currently cared for at Kenyatta who were HIV positive ranged from 10 to 30 percent. These figures are reflected in several recent studies, which found 13 to 25 percent HIV prevalence among pregnant women who were tested.[8] Although the disease realities for HIV patients cannot be conveyed through these variable statistics ("statistics are sufferers with the tears wiped dry," as one of our colleagues reminds us), the magnitude of the number of AIDS patients at a given time or in a given ward has drastically altered the experience of medical-school faculty, student physicians, and health-care workers.

In such settings, the HIV pandemic strikes at the heart of medicine, challenging the profession's ideals, ways of learning and knowing, and essentials of basic patient care. HIV/AIDS has led to a demoralization of medical faculty, eroding fundamental intellectual assumptions about medicine as a system of knowledge as well as a helping profession. Ethical dilemmas arise from the brute fact of the disease, which compounds and is compounded by poverty, a scarcity of resources, and deep inequalities of wealth within and between societies. It is Dr. Amayo's voice we hear in this conversation, but it is also the voice of the profession of medicine bereft of its cultural power

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and instrumental efficacy. The dilemmas Dr. Amayo poses are the dilemmas of academic physicians who struggle with how to remain intellectually engaged in medicine in this context, how best to teach diagnostic and curative medicine when many of the patients who provide "teaching cases" are HIV positive and sufferers of AIDS, and how to cope with the futility of everyday practice.

"Medicine is Supposed to Challenge Your Mind": The Problem of One Disease Pattern

Dr. Amayo spoke about the threats to medicine's intellectual integrity that arise when a single disease pattern—for example, the HIV symptoms diarrhea, cough, and fever—obliterates "what medicine is supposed to be about."

> It makes you feel you may lose in your area of interest—your proficiency, your particular area, and even your particular [ability at] solving diseases. Because you have one pattern that comes all the time . . . diarrhea, cough, fever . . . and that pattern is all over. Even in ward rounds. It is no longer interesting because there is nothing challenging. Because medicine is supposed to challenge your mind—O.K., this may be this disease, that disease, and lead to some kind of discussion. . . . Now it goes to the extent where you arrive at the door and the diagnosis is obvious . . . before it was much more interesting. Now patients, who are in sight but . . . you don't really see them . . . like so much wheat you don't see the other important crops for that.[9]

A loss in the variety of disease patterns not only threatens the intellectual vitality of medicine; it has consequences for teaching medicine to medical students and residents.

> The basic thing in teaching . . . you want to have something that is challenging the students and you to eventually reach a diagnosis, and that was what medicine was supposed to be—to tax your mind, with a differential diagnosis, and do the investigation and come up with the diagnosis. And when that one lacks, medicine becomes very—it does not become anything academic—and now it's just looking into the ward. It doesn't intrigue you anymore.[10]

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Dr. Amayo believes that medicine is a calling. He reflected on what he imagined, when he entered medicine, would be the satisfaction gained from helping patients.

> I imagined I would treat people who would walk in sick and walk out healthy, and I would like to meet them in the streets and say O.K., this is one of the people I treated who was very sick, and, and that was my imagination and what I would get most satisfaction from. There used to be cases in which there was nothing one could do, but those were not the majority. As time went on, it ended that the majority are [needing] close to terminal care, rather than the other way around. So that—now it's a moral selection . . . —for what [do] you bother?[11]

I asked Dr. Amayo whether he was overwhelmed by the overcrowding in the hospital. Unlike a few years earlier, when I first visited Kenyatta, by 1997 patients were sharing beds—"by volume," as Dr. Amayo noted. "If you are small, you share." As a result, some patients who did not have HIV infections when they came in, perhaps for heart disease, were leaving the hospital with HIV or with TB—contaminated by a lack of isolation. And yet even this is not what most overwhelms physicians.

> It is not the overcrowding, because if there was overcrowding and they were going away walking, O.K., but *this is an overcrowding of death. A wing by wing, a massacre.*[12]

This "overcrowding of death" disempowers physicians. It erodes their sense of competence and threatens the most basic goal of medical education—instilling this sense of competence in a new generation of physicians, an embodied ability to respond to human suffering in an effective manner.

> Students fear . . . their biggest worry is that they will not be recognized [as competent physicians with requisite skills acquired in patient care]. The recognition is more frightening; doing something for somebody is no longer the norm. And when you come out of the system, you are so numbed at that initial level, because there should be an ideal. So you are seeing the worst . . . people complain that new doctors don't care, and about their competence and training. Crowding and inability to do something leads to a numbing of students.[13]

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Thus, the moral sensibility of physicians is challenged, Dr. Amayo reflected, by the inability to do anything. It is not poverty or scarcity but the HIV plague that is devastating medical idealism. It is a primary reason clinicians drop out of medicine and move into research, public health, or business.

Interviews conducted by Dr. Machoki and Dr. Amayo with other faculty physicians and with medical residents suggest that Amayo's views are widespread. A senior faculty surgeon interviewed in February of 1999 by Dr. Machoki remarked:

> Too much emphasis is directed at discussing and researching HIV/AIDS and related infections, such that there is not much time left for other disease conditions. This is not fair to students and of course to other patients who are suffering from other conditions. The future of the profession is in jeopardy. If no measures are taken to arrest the situation, we are going to train doctors who know nothing else except HIV/AIDS. That is the danger I see. It is a big problem. Money and other resources are scarce, HIV/AIDS demands are growing, and the future of medical care is grim.[14]

Residents interviewed also worry about how HIV/AIDS has affected the training context. A second-year resident in obstetrics and gynecology noted:

> HIV/AIDS . . . affected training in that most patients . . . tend to stay longer in hospital, leading to a lack of variety of cases. . . . Doctors have a tendency of doing quick rounds by only saying "CT" [continue treatment] without much discussion. . . . Most of these patients are depressed and are no longer open to the staff.[15]

RESPONDING TO CLINICAL REALITIES

If the overwhelming "disease entity" provides a generalized threat to the cultural power and instrumental efficacy of medicine in the local world of East African medicine, it also provides quite specific moral challenges to and creative responses by academic physicians. Dr. Mwaikambo, former chair of pediatrics at Muhimbili Medical Center and currently vice chancellor of Herbert Kairuki Memorial University, a new private medical school, characterizes medical teaching as a "coping struggle" for academic clinicians. A central ethical challenge facing pe-

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diatricians in Tanzania, she says, occurs when children test positive for HIV and doctors must reveal the diagnoses and prognoses to parents, one or both of whom may well be HIV positive—with or without their or their spouse's knowledge—and thus may be responsible for their children's impending deaths. Teaching pediatric residents how to disclose the diagnosis of a child's HIV status, when the consequence of disclosure may be the social destruction of the family, presents very specific dilemmas. Efforts to counter the sense of being overwhelmed by the burdens of disclosure, to help residents learn to communicate the news of this affliction to parents, pose a specific challenge for academic physicians. Dr. Mwaikambo has launched a new program in medical-ethics research and education to investigate ways to teach medical students and residents how to counsel patients and families.[16]

An alternative mode of "coping" in Kenya was illustrated when I joined the director of Kenyatta National Hospital, Dr. Julius Meme, and Dr. Amayo for a tour of the hospital in October of 1997. After visiting "Ward 23," where HIV patients overwhelmed the service and beds were shared, we visited the newly constructed private offices and private services and the newly equipped intensive care, cardiac catheterization, and nephrology units of the hospital. These units, mixing public and private forms of care, were an attempt to offer the best quality of medical care available in Nairobi. To Dr. Amayo and other physicians, they offered a respite from the burden of care for the terminally ill and a place to teach curative medicine to medical students and residents.

Such a multitiered system would previously have been regarded as inappropriate for the national public hospital, a challenge to the ethics of the equity of care that was internalized by Kenyatta's earliest generation of physicians. In the current context, however, the system appears to enhance physician morale and thus the moral voice of the professionals who must teach medical students while working in daily contact with many terminal patients. And yet many of Kenyatta's physicians, including the former hospital director, expressed a sense of unease, perhaps of guilt, because they cannot treat all patients equally. Nevertheless, in January of 1999 the multitiered

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system was flourishing and the private services had expanded to additional units. Academic physicians who provide patient care in public clinics were being encouraged to establish private clinics in the new clinical spaces built by the hospital, thereby ensuring the referral of "patients of means" to the private wards and a continued flow of resources into the national public institution.

The "political economy of hope" in this context creates an unresolvable dilemma.[17] The privatization of care and the public/private mix creates hope for the academic physicians—hope to make the hospital financially viable, hope to offer training situations for students to learn medicine other than on HIV wards, hope to hold on to the intellectually engaging aspects of academic medicine, hope to maintain one's sense of humanity in the face of an overwhelming disease entity and death—as well as hope for patients able to afford a higher quality of care and, nationally, hope that the scourge of AIDS can be addressed by Kenya's medical system. At the same time, it institutionalizes inequities in the quality of care provided to patients, threatening an ideology of equity that previously governed the hospital's organization.

John Iliffe, a historian of East Africa teaching at the University of Cambridge in England, recently published *East African Doctors: A History of the Modern Profession.* Iliffe presents a densely detailed historical account of the rise of modern medicine as a profession over the past century in East Africa (Uganda is his major focus, but he also includes brief histories of the medical profession in Kenya and Tanzania). He examines the ambiguous relationship between power, knowledge, altruism, and wealth, and the relationship of the profession to the state, particularly in the domain of public health and most recently in AIDS-control programs. He also documents the epidemiological research on HIV as well as the various biomedical adventures of vaccine trials and new drugs of dubious promise of the past decade. Throughout this book, Iliffe frequently calls for social studies of the profession and argues that little is known about the power, prestige, culture, and practice of the profession as it stands today. He notes:

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> Sociological studies of the contemporary medical profession are especially needed, but so is a programme—which must be conducted by East Africans—to collect the life histories and papers of modern doctors.[18]

He also suggests that

> In the West, the constellation of stress surrounding AIDS caused among doctors and other health workers the emotional and moral exhaustion known as burnout. Remarkably little is known about this in East Africa, despite the greater scale of the epidemic there. Some suggested that circumstances in poor countries were so different that Western experience of burnout might be irrelevant, but Sewankambo (Uganda) warned that the phenomenon was to be expected and there were reports of health staff leaving or refusing to work. . . .[19]

My East African colleagues (Mwaikambo, Machoki, and Amayo) and I have begun just such an exploration about how the HIV/AIDS pandemic is related to physician burnout, moral actions, and the ethics of care as well as to the continuation of the profession. The serendipitous publication of Iliffe's historical account has provided a solid foundation for the investigation of the relationship between local and universal moral dilemmas and the culture and power of the medical profession to execute agency and to choose how the profession will be reproduced in the future.[20] Although the foci of our current investigations are local and explore the ethical and moral issues in medical education and practice within Kenya and Tanzania, moral dilemmas of a transnational nature also arise. As younger physicians and medical students begin to regard AIDS or HIV positivity as a chronic disease—"not all that different than malaria" remarked first-year residents in obstetrics in a focus-group discussion in January of 1999—they ask not only how they can gain the knowledge to best manage cases competently to treat opportunistic infections and to maintain the health of patients as well as possible given limited resources for the purchase of accessible medications, but also how they can access the new pharmaceutical cocktails, reduce the costs to their patients, and develop enough political will to challenge the pharmaceutical companies to live up to their promises of pro-

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viding effective drugs for feasible cost in Kenya and Tanzania. (Glaxo-Wellcome had promised to provide AZT for pregnant women for $50 for a cycle of treatment rather than the first-world cost of $1,600, but acquiring these drugs is difficult; physicians must seek the reduced-cost drugs on behalf of their patients and negotiate directly with company representatives in company offices.) When per capita income is approximately $120/year in Tanzania and $350 in Kenya, acquiring pharmaceutical treatments for AIDS victims or those afflicted with HIV becomes a moral agenda of a global order beyond the debate over intellectual property.[21]

PRELIMINARY CONCLUSIONS: AFRICAN DILEMMAS

Four major domains of moral "dilemmas" emerge out of these preliminary explorations with our East African colleagues. First, academic clinicians are concerned about how to preserve medicine as an intellectual enterprise in the face of the HIV plague. The academic profession holds as one of its goals not only treating patients but also producing competent physicians and upholding "universal" standards of biomedicine as an ideal. This ideal is clearly grounded in much of what drives medicine globally—the challenge of diagnosis, the excitement of curing diseases or at least the potential to stem the consequences of disease and to manage illness, the access to pharmaceutical resources and technology that makes doctoring intriguing, gratifying, and a modern enterprise.

The second domain is how the HIV disease plague threatens the ideals of "doing good," of what is regarded in any medical setting as "good doctoring" and quality patient care. In our interviews, we find academic clinicians in a quandary—if they bemoan the assault of HIV on medicine as an intellectual enterprise, they fear accusations of professional self-interest, of patient abandonment (CT, "continue treatment," or medicine from the doorway), and withdrawal from engagement in quality patient care. Yet, as my colleagues Machoki, Mwaikambo, and Amayo note, if they do not speak in academic medical settings about these difficulties and about what they see as the failures in the care of HIV patients in medical practice, there

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will be no way to correct errors in clinical behavior, no brake on withdrawal from patient care, and no discussion of the ethics of care. Here they identify the problems as multifold. Most obvious is the fundamental problem of communication with patients with HIV/AIDS: how to disclose information about diagnosis, disease, and limited treatment options; how to establish and create therapeutic relationships with patients when the system within which most clinicians work is not conducive to "counseling" and spending time with patients; how to care for and counsel patients when physicians themselves feel unable to carry out these activities because of personal fears of disease and, especially for more practiced clinicians, the sense of "burnout" that comes from working with patients who have terminal illnesses. Residents in our focus-group discussions and faculty colleagues also note the problem of the silence maintained within the academic hierarchy. Few faculty physicians explicitly teach how to counsel AIDS patients, how to disclose HIV status, and how to care over time for patients—to treat AIDS and associated diseases as chronic disorders; even fewer "model" behavior and discuss cases at length with residents in training. My colleagues argue that an unhealthy silence surrounds much of medical practice and training in the management of patients with HIV/AIDS-related diseases.

The third domain of ethical and moral dilemmas is one that is grounded in the political economy of medical care in East Africa and the international global market: the inequities, the scarcity of resources, the implicit and explicit rationing of therapies in terms of time and pharmaceuticals are all part of daily practice. The discrepancies in medical resources between Kenya or Tanzania (a far poorer nation than Kenya) and the wealthier nations have existed throughout this century. Nevertheless, it is evident from our preliminary interviews and discussions that in recent decades, prior to the onslaught of HIV/AIDS, faculty physicians felt that they could often access medical resources and pharmaceuticals that were available elsewhere. The HIV pandemic, however, has brought the issue of economic discrepancies between the wealthier and poorer nations to the forefront of the global discussion about inequality. African physicians are aware of the new pharmaceuticals that

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have made HIV/AIDS a chronic disease in the West; they also know that the ready availability of antibiotics to treat associated infections can prolong life. Residents are anxious to learn about these treatments yet rail against the economic and political barriers to accessing not only the more costly therapies and protease inhibitors but also the basic antibiotics that many of their patients can ill afford. Again, the dilemmas and quandaries of clinicians who raise questions about "doing good" for individual patients are also tied to questions about how to manage a world pharmaceutical system that holds out the potential for care that is efficacious but that remains out of reach for most of the society. East African clinicians are beginning to be more aware of these institutional- and system-level constraints and are speaking about changing approaches to training and communication within the training hierarchy and about taking more proactive approaches to address the political and economic issues associated with access to therapies for HIV patients. Even within their own training institutions, such as Kenyatta National Hospital, both faculty and residents must address the private/public systems that allow for the reproduction of medicine as a profession and an intellectual enterprise through a multitiered system of medical care that gives higher-quality care to wealthier patients.

The fourth domain of ethical dilemmas and moral quandaries for East African physicians centers on how to redefine the care of HIV/AIDS patients from curative medicine to palliative care and the management of associated diseases. In Dr. Amayo's presentation to the Conference on Health and Social Change in East Africa in 1999, sponsored by the department of social medicine at Harvard Medical School, he sought to move beyond the dismaying images he painted for me in his earlier interviews (as noted above) and to develop a plan of action that would reenergize the teaching of the profession and tie it to an improvement in the quality of care for AIDS patients in Kenyatta's medicine wards. He noted the importance of teaching how to manage AIDS-related infections, to give appropriate care in the interval between HIV positivity and death, and to provide compassionate and competent palliative care. This shift challenges the dominant curative modes of contemporary medicine,

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be it in Africa or the United States. Yet it also suggests one way to preserve medicine's intellectual enterprise—to expand it from the definition previously given by Dr. Amayo to include palliative care in the extreme and the management of chronic diseases in the moment. Such an enterprise, combined with other activities of our colleagues to raise the ethical dilemmas and identify the failures of medicine and medical education as currently practiced, may deepen and expand what medicine cares and should care about in Kenya and Tanzania.

These explicitly "professional" moral and ethical dilemmas as defined by our physician colleagues highlight tensions between the dire local situations clinicians face and the unequal power relationships of global and market medicine that affect the experience of local doctoring. These tensions and the discrepancies they mark suggest deeper East African historical experiences with colonialism and nationalism as well. Although many contemporary East African academic physicians received advanced training in Europe (especially in the United Kingdom), North America, or the former Soviet Union, physicians also have been exemplars of nationalist, postcolonial, and modernist projects, including socialism in Tanzania and capitalism in Kenya. In each state, generations of postindependence physicians (1960s-1990s) surmounted barriers of colonialist policies that restricted professional training and limited the distribution of medical knowledge.[22] As members of a global profession with a system of shared knowledge, East African physicians possessed symbolic (modernist, nationalist) power; many could at least partially counter and transcend the colonial legacies of domination and racism through their clinical and educational work. As a professional group, physicians also became among the wealthiest of their compatriots, at the pinnacle of hierarchies of prestige and often of social and political influence. Since being "overwhelmed by HIV disease entity," the symbolic power of East African physicians, as well as their instrumental efficacy in daily doctoring—their ability to practice medicine at the level to which they were trained—has come under assault. Although the HIV pandemic's insidious consequences are most observable in the devastation of families and communities in East Africa (and in sub-Saharan Africa in gen-

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eral), modern postcolonialist institutions and their successes—such as medicine, health-care systems, and the health status of the East African peoples—have been undermined but certainly not destroyed.[23] Nevertheless, many physicians have withdrawn from public practice and have fled to the private sector, investing their efforts in the care of patients without HIV.

MORAL DILEMMAS OF AN AMERICAN KIND

The second part of this essay addresses moral dilemmas and ambiguities of an American kind in high-technology medicine. The materials presented are from my studies of the culture and political economy of American academic oncology as practiced locally in academic medical centers and as influential globally in establishing standards of treatment and research.[24] The focus, for the purpose of this essay, is on how academic physician-scientists consider and at times promote experimental and salvage therapies, such as bone marrow transplants and autologous bone marrow transplants. These procedures have rapidly moved from "experimental" to "standard practice" for treating metastatic cancers, yet the therapeutic efficacy is regarded as ambiguous at best. This American case raises ethical questions about whether "doing" is "doing good" and about how medicine as a research and experimental enterprise can be overwhelmed not by disease entity but by an ambiguity of therapeutic efficacy and by a powerful political economy of hope.[25]

I chose this example from American academic medicine, which is at the opposite extreme of medicine's therapeutic resources from the East African case discussed above, in order to tease out that which is common or "universal" to professional moral discourses and that which is markedly local and uniquely framed by local history, political economy, culture, and dominant disease patterns. Although local moral worlds and ethical dilemmas are emphasized, professional ethical and moral decisions of East African academic physicians and American academic oncologists, I suggest, are not totally divorced. A commonality of dilemmas arises out of the ambiguities of all medical practice—concerns about "doing good" when disease is severe or

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terminal and when the therapeutic efficacy of treatment options is questionable. Economic distinctions between the two cases are, of course, most extreme. American culture's embrace of innovation in biotechnology and, in particular, societal investment in anticancer therapies and high-technology medicine in general (including the research that has led to the production of protease inhibitors to treat HIV) fuels a flourishing biomedical industry, a political economy of hope. East African academic physicians can but rarely access the benefits of this political economy of hope even when knowledgeable about its therapeutic "products."

AMERICAN ONCOLOGY AND THE POLITICAL ECONOMY OF HOPE

> . . . it's exciting, but it's a different brinkmanship. And I think for that reason you do it in a sophisticated world only, where you have checks and balances. . . . What they actually get out of the transaction is where they are talking, and that is a separate mode, and I don't think they collide really. It's a schizoid way in which you operate. One is talking to people and the other is figuring out the best way to go for it. And then telling what risks there are, and that we are very blunt about. You have to do that.
>
> —Radiation oncologist discussing experimental treatments

American academic oncologists live in worlds of vastly apparent differences from most of our East African academic colleagues. Research oncologists in particular stand between the biosciences of their specialties and the clinical tasks of caring for people with serious and life-threatening disease that is often resistant to treatment. The "schizoid way in which you operate" identifies two worlds in oncology—the scientific, often experimental, domain of cancer treatment and the therapeutic domain of patient care. Oncologists debate how best to join these two worlds, how best to master the ambiguity inherent in many aspects of their work. As physician-scientists, they must encourage patient involvement in clinical trials and experimental research protocols; as providers of care they are expected to give priority to patient well-being. In this world of American academic oncology and high-technology medicine, physicians

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are expected to invite patients to consider experimental options when disease is resistant to standard treatments.

It is through invitations to "salvage therapy" that oncologists wed the experimental to the therapeutic, revealing specialty and subspecialty power as they instill a desire for treatment, plot a therapeutic course, and give hope even though such treatments are often of questionable efficacy. The political economy of hope drives clinical actions, justifying treatment decisions, but it also raises moral and ethical questions for clinicians well aware that the options offered are indeed "salvage" at best and often do harm. In the American case, academic oncologists practice an "aesthetics of statistics," incorporating findings from clinical trials to introduce therapeutic meaning into their discussions with patients. Statistics, conveying odds and chances of particular treatments, are institutionally sanctioned, taking on a centrality in oncologists' clinical narratives even as ultimate questions of death are skirted, and the immediacy of initiating therapeutic activities is addressed. Patients' ironic engagement with their clinicians, as they negotiate the meanings of the odds and statistics, of the fantastic and questionable, provides a glimpse into how the medical imagination engenders a certain bravado, a many-possibility experience, that supports and sustains emotional, financial, and cultural investments in experimental medicine.

The current controversy over the efficacy of autologous bone marrow transplant (ABMT) treatment for advanced primary and metastatic breast cancer illustrates the moral dilemmas encountered in the uncertain worlds of oncological practice. As an academic medical oncologist noted in 1993 at the beginning of our study on clinical narratives in oncology, this expensive "salvage therapy" had dubious therapeutic credentials; in clinical trials to that date, patients who initially responded positively to transplants "were all relapsing at six or eight months after the transplant." Yet in 1994 several patients sued their insurers who refused coverage for ABMT treatments, and many more medical oncologists encouraged their use. A now infamous suit brought by a California Kaiser patient who was refused coverage in 1994 helped to establish this "experimental treatment" as a standard of care by 1995–1996. Michael Zinner,

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Chief of Surgery for Partners and Harvard Medical School, noted in a 1996 presentation to Harvard medical students that "No HMO would be able to refuse coverage now because of that suit."[26]

Research oncologists invested in the procedure argued that new clinical studies indicated that mortality *from the procedure* decreased from 30 percent to 3 percent as innovative care was introduced and healthier patients were recruited. Even though the cost of providing ABMT or stem-cell supportive therapy has declined dramatically (from approximately $150,000 in 1993 to $60–75,000 in 1995, to approximately $60,000 in 1999), even though the technological fix has become increasingly efficient and standardized and treatment locales have shifted from hospital to outpatient services, therapeutic efficacy continues to be questioned. As the bioscience of the field alters (shifting rapidly from ABMT to peripheral stem-cell support) and decisions to choose competing therapeutic options become ever more complicated, especially given the uncertain efficacy of high-dose chemotherapy with ABMT and the potential for serious clinical errors (recall the errors at the Dana Farber Cancer Institute), the therapeutic journey has to be carefully orchestrated. Although they are aware of questionable efficacy, we find patients and physicians excited by the possibilities of these experimental therapies.[27]

Clinician-scientists such as Dr. Peters of Duke University Medical School are among the public promoters of the ABMT experimental therapies, normalizing the technologies and the apparent high-tech oddities, turning the unusual into an event no more odd than a coffee break. An excerpt from Peters's testimony during the federal hearings on whether Medicare/Medicaid would support coverage of ABMT for metastatic disease illustrates his persuasive normalizing approach (accompanied by slides of patients who were undergoing the new procedure).

> As our famous philosopher once said: "the future just ain't what it used to be"—this is what most people think of bone marrow transplants as being—a high technology facility with isolation procedures, use of high-tech equipment, multiple supportive care efforts and so on. What is really happening is that, in the last few

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> years, this is occurring more frequently. Two women from our institution—[one] on day two and [one] on day six of their bone marrow transplants—are waiting for coffee to be delivered to the hotel where they are staying during their bone marrow transplant. (Shows two slides of women; how routine, how normal, how unremarkable.) We now essentially do all our bone marrow transplants as outpatient procedures. If one looks at the 100 day mortality in patients undergoing transplants, you can see that, back in the mid-1980s, the therapy-related mortality in the first hundred days was at over 30 percent. Now, it is down in the range of about 3 percent. In fact, if you look at the 30 day mortality shown here, again, from 15 percent down to the 3 to 4 percent realm. This represents massive change in therapy-related mortality.[28]

AMERICAN ONCOLOGY'S CLINICAL REALITIES: ENCOUNTERS WITH THERAPEUTIC AMBIGUITY

Such clear descriptions of "success" do not necessarily translate into quality patient care, nor do they provide clinicians with clear moral choices. Interviews with the oncologists of patients who were potential candidates for bone marrow transplants as well as recorded clinical interactions between patients and their physicians highlight the difficulties of educating patients and guiding decisions when "therapeutic choice" offers uncertainty and some threat of harm. Patients who were interviewed after meeting with their oncologists would at times misinterpret their "risk" category and the potential benefits of the interventions, as well as misunderstand their clinicians' descriptions of protocols for ABMT. Yet patients used metaphors that captured the ambiguity of ABMT—likening such therapies to "the twilight zone," "the bizarre," and "the archaic" and imagining their clinicians as Frankensteins asking "what are we going to make today?" Such ironic comments are echoed in BMT-Talk, a cyberspace network for patients considering or undergoing BMT/ABMT procedures. Patients who have undergone BMT or other experimental therapies—even those who have a very clear understanding of the implications of such treatments and who have "gone for broke"—ask themselves and at times their oncologists "when will [experimental treatments] be enough?"

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Oncologists who participated in these studies posed similar questions to themselves as they reflected upon the recommendations they make to patients and questioned the way they present therapeutic options and craft treatment journeys. And yet it appeared to me that by late 1996, when we had followed breast cancer patients through eighteen months or more of treatments and checkups, the medical oncologists who initially were highly vocal about the questionable efficacy of ABMT were offering it to more patients and to healthier patients (with lesser lymph node involvement than women involved in the protocols in the clinical trials). Treatment without the benefit of extensive clinical trials had become normative, routinized care. Many reasons underlie the routinization of ABMT for metastatic breast cancer: patient pressure and interests of the breast cancer social movement were certainly significant; the procedure had become safer and cheaper, and was covered by insurance; the oncologists could offer a possible cure to patients who were otherwise at a loss. The machinery of medical industry and the political economy of hope were clearly implicated.

In 1997, preliminary information indicated that ABMT might grant women suffering from metastatic breast cancer a greater chance of containing the disease and extending their lives. In the spring of 1998, several oncologists who were initially uncomfortable with the ambiguity of early results had opted to work within the norms of routinizing "experimental treatment." They noted that within research and academic oncology, questioning voices are often silenced, particularly regarding the efficacy of salvage therapies that become normative and routine for patients as well as for oncologists. Ironically, many of my oncologist colleagues thought that the economic constraints of managed care linked to "evidence-based" medical practice would likely force this discussion into the public domain, at least in corporate corridors.

In April of 1999, the American Society of Clinical Oncology (ASCO) released findings on their web site from five studies on the comparative efficacy of standard therapy versus high-dose chemotherapy with and without ABMT and peripheral stem-cell supportive therapy in treating advanced breast cancer, thereby breaking news to the public prior to the presentation

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and discussion of study findings at the American Society of Clinical Oncology meetings on May 15–18, 1999. The ASCO summary of the preliminary results of the five studies sounded many cautionary notes: "conclusions drawn from these studies only apply to cases that meet these specific criteria":

> Three of the studies discussed here examine the use of high-dose chemotherapy and bone marrow or stem cell transplant in the adjuvant treatment of women with very high-risk primary breast cancer. "Very high-risk" in these studies is defined as cancer that has spread to at least 10 lymph nodes.
>
> Two studies examine the use of high-dose chemotherapy for the treatment of advanced, metastatic breast cancer.
>
> The preliminary results of three of the phase III studies accepted for presentation at the plenary ASCO meeting and a poster presentation indicate that high-dose chemotherapy with bone marrow or stem cell transplant and standard, lower doses of chemotherapy result in equivalent survival. High-dose chemotherapy is statistically superior in one plenary study.
>
> One study showed a delay in relapse for ABMT patients at three years but nearly identical recurrence and mortality rates at five years, suggesting better quality of life and a lengthier "off therapy" period.[29]

Although in recommendations for patients and physicians ASCO emphasized that "it is not yet possible to draw definitive conclusions" and that these findings provide "preliminary insight, not the final word," the data were released to add to the clinical science that oncologists must bring into discussions about treatment choices. ASCO argued that "the process of clinical research is necessarily time consuming" and pleaded with insurers: "because clinical trials are such a critical part of cancer treatment and research, insurance carriers should be required to cover the routine patient care costs . . . associated with participating in clinical trials."

This ASCO web-site document (at www.asco.org) is intriguingly political, a master narrative of uncertainty and ambiguity that lies at the heart of much clinical and research oncology. ASCO's moral agenda is not masked—insurance coverage, management of uncertainty in decisions and choices, and use of preliminary data from clinical trials are explicitly addressed—

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and yet considerable media and public controversy ensued, as the detailed press coverage competently highlighted "doubts."[30]

What are the everyday moral dilemmas in the ABMT story? Do our clinicians dare to tell us "when it is enough"? Does the political economy of research medicine, of anticancer therapies such as BMT, create barriers, ambiguities, and silences where there perhaps should be greater disclosure and debate? Or does the very ambiguity of the situation—of life-threatening disease without clearly efficacious and inexpensive modes of cure—create multiple truths expressed not only from within clinical and research medicine, nor only from the industries of bioscience and biotechnology, but from the public and patients with diverse interests as well? Is this ambiguity and complexity what intrigues and energizes the profession of medicine in America and what leads American society to invest so much of our social and cultural resources in high-technology medicine? Does this ambiguity define at least in part, morally and ethically, what our society wants medicine to care about?

MORAL ACTIONS AND ETHICAL QUANDARIES: UNIVERSAL? GLOBAL? LOCAL?

If we return to the suggestion posed by Arthur Kleinman that a distinction be made between a codified body of abstract knowledge about "the good" and the moral commitments of social actors in local worlds—in our case of academic clinical medicine—several intriguing issues arise. When we compare the two examples discussed above, we find on the surface many differences in clinical burdens and possibilities. Moral action is obviously of a different order in each context, as resources define, at least in part, standards of "doing good," and clinicians struggle with the limits of care in highly different social and economic contexts. East African physicians are compelled to deal with shortages and inequalities that too often turn the standard of care for HIV patients toward placebos or toward no medical treatment at all. Conversely, American oncologists are compelled to weigh the often excess availability of treatment possibilities against the uncertain enhancement of the quality of life for patients. American physicians who care for

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patients at the end of life frequently question the utility of many of oncology's salvage therapies, including BMT procedures.

Despite these differences, East African academic physicians do not live in radically different professional or scientific worlds from American physicians. They follow contemporary biomedical developments, are market targets of international pharmaceutical firms, and participate in international conferences on new technologies and on the ethics of patient care as well as on HIV/AIDS. Medicine as a global science and market *and* as a profession powerfully provides "universals" that our colleagues participate in and seek to reproduce. Programs designed to improve the training of medical students and residents, to enhance physician competence, to influence the ethics of practice, or to raise the quality of patient care appeal to these professional "universal ideals." That the "universal standards and ideals" historically have been formulated at centers of academic medicine in the West appears largely unproblematic for many physicians who have internalized these professional norms and made them part of the modernist enterprise of African academic medicine. Indeed, these physicians appeal to the universals of medical science and practice to define what "good" ought to be in daily clinical practice and to determine what moral challenges physicians ought to address, even as they live in radically different worlds of therapeutic resources for patient care and clinical practice. What, then, are some commonalities that weave through these two cases?

First, dilemmas about disclosure resonate across these two cases, although in culturally distinctive ways. Physicians choose when and how much to tell patients—not only about their diseases and diagnoses but also about therapeutic possibilities. In East Africa, the tradition of physician-patient communication has been paternalistic and the nondisclosure of information about disease and treatment has been the norm, especially in the treatment of women.[31] However, the HIV pandemic has challenged physicians to rethink these traditions of nondisclosure with HIV patients and in other areas of medicine as well. Patients often do not wish to have their HIV status acknowledged, for the stigma of the disease has devastating consequences for a person's social relationships, as noted by

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Mwaikambo. Causes of illness and death have been masked by patients, family, and physicians. Yet many academic physicians are beginning to believe that patients must be told their HIV status and counseled about the consequences for their family and for other relationships in order to help stem the sweep of the epidemic. Further, some physicians believe that even when they assume patients cannot afford AZT or protease inhibitors, patients have the right to be aware of therapeutic possibilities, in case family members or communities can support treatment. Although the disclosure of cancer diagnoses is far less contested and is becoming an international norm, oncology as practiced in the United States has furthered debates about how much detail about prognosis and therapeutics should be told to patients. But even in the United States, professional silences about the limited efficacy of new therapies such as BMT or peripheral stem-cell transplants with high-dose chemotherapies are common. The ASCO information release creates challenges for oncologists—how indeed to explain to patients, in this era of frank disclosure, the complex ambiguities of clinical science and the uncertainty of therapeutic innovations. Thus the problems of disclosure and truth-telling crosscut both cultures of medicine and highlight the tensions between academic medicine, clinical science, and traditional norms of clinical practice.

Second, the intellectual enterprise of academic medicine, as exemplified by these two cases, clearly places the treatment of patient suffering and end-of-life care at the margins of biomedicine. Walter Robinson, pediatrician and ethicist at Harvard Medical School, notes the similarities in the African and American examples. He suggests that the treatment of "suffering" and the care of terminal patients have low status and priority in both contexts. What is exciting for academic clinicians, especially physician-scientists, is to be on the cutting edge of medicine, to develop innovative therapies, to be challenged by difficult diagnoses—as Dr. Amayo noted, "to challenge one's mind." This intellectual enterprise and the values espoused make medicine an attractive profession. Yet these values, which give priority to curative and diagnostic medicine, can compromise patient care at the end of life, whether in the academic medical centers of Kenya, Tanzania, or the United States. Is the

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extreme interventionist approach of some American oncologists followed by abruptly discontinued attention (although not necessarily technology) when patients become terminal that far removed from what our East African colleagues and residents have sharply labeled as "continue treatment"—the unengaged and uninterested "CT"—or release to home, until death comes? Comparable responses generated by these ethical dilemmas experienced by physicians from both continents include the palliative care movement in the United States and a more recent turn to addressing failures in the quality of care and attention given to terminal AIDS patients in East Africa. Although the palliative care movement in the United States is far more developed, both responses appear as reactions to the dichotomies of an "either/or" approach to the care of patients with terminal illnesses.

Third, the political economy of medicine is fundamental to academic medicine's enterprises, to the reproduction of the profession, and to the future of bioscience and biomedical innovations. East African physicians face the brute economic and political constraints that require them to engage in explicit and implicit rationing, whether it be the availability of beds, basic medical equipment, and drugs, or the more spectacular limitations of pharmaceuticals to treat HIV/AIDS patients.[32] The international sanctions against companies manufacturing drugs at a lower cost than the companies that hold the patents have angered African physicians who cannot readily access the new therapeutic treatments, the protease inhibitors, or even the less expensive AZT or ddI that prolong life, available to many patients in the West.[33] Thus, both the mundane and spectacular limits on medical resources are part of daily practice.[34] Oncologists in America also face dilemmas of how to guide patient choice when limits to care loom from the for-profit managed care corporations and from larger societal inequities. The forty-five million uninsured Americans become part of the discussion among oncologists and the ASCO about whether experimental or salvage therapies can be offered to patients depending upon their insurance status.

Fourth, moral voices are fundamental to the reproduction and power of the profession. Medicine's enterprise to produce

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physicians who will practice competently has often been complemented by exhortations by its academic and political leaders to produce physicians who will practice compassionately and equitably as well. These values have a "global" quality that bridges the differences in local clinical realities. My East African colleagues have acquired a focused interest in medical ethics and in changing the ways senior faculty teach and communicate with students and junior staff.[35] This recently formalized interest in ethics and the innovation of professional training has a quality of moral regeneration, perhaps an antidote to the "numbing" of professional idealism that has occurred over the past decade due to demoralization in the face of poverty, limited medical resources, and in particular the disease plague of HIV/AIDS.

Academic medicine in the United States has a long history of cultivating professional "moral voices." As we observe maturing physician-scientists, it is apparent that cultivating a professional moral voice earns one cultural capital, perhaps a prerequisite for entrance into medicine's elite, as well as a resource to invest in formulating institutional medical ethics and in shaping local as well as national and global ethical debates. Such debates address the tensions inherent in carrying out clinical science and patient care, in guiding patient and family choices in the face of uncertainty of therapeutic efficacy, and in rationing resources in response to institutional and economic limitations. These ethical debates have spilled into the public domain via the media and have challenged oncology as a specialty to examine closely the benefits of experimental and salvage therapies, and to consider the treatment of suffering through a more highly attentive approach to palliative and end-of-life care—some of the many difficult clinical realities that frame ethical issues for American academic oncology and for American medicine at large.

The universal or global values of the profession of medicine, whether practiced and taught in the local academic medical centers of East Africa or the east coast of the United States, drive much of what medicine as an intellectual enterprise cares about: what it means to be a physician, to practice good medicine, to do good and provide quality care to patients, to teach

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and reproduce the profession through the training of competent clinicians. My physician colleagues from both settings note that it is often difficult to sustain reflective and critical perspectives and to engage in meaningful ethical discussions of moral dilemmas of medical practice and training. In some academic medical settings, both in East Africa and in the United States, it is politically difficult and sometimes professionally dangerous to acknowledge openly medicine's failures and shortcomings. Yet in both cases we observe the critical and reflective voices of members of the profession articulating dilemmas encountered in their local worlds of clinical reality, struggling with how to define what medicine should care and be about.

ACKNOWLEDGMENTS

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ENDNOTES

[1]Arthur Kleinman, *Writing at the Margin* (Berkeley: University of California Press, 1996), 42.

[2]Ibid., 45.

[3]Mary-Jo DelVecchio Good, *American Medicine: The Quest for Competence* (Berkeley: University of California Press, 1995); Good, "Cultural Studies of Biomedicine," *Social Science and Medicine* 41 (4) (1995): 461–473; Good, "L'Abbraccio Biotecnico: Un Invito al trattamento sperimentale," in *Il sapere della guarigione*, ed. Pino Donghi (Spoleto, Italy: Laterza, 1996), 25–62; Good, "Medical Ethics Education: World Trends and the Harvard Experience," *Journal of Medical Education* (National Taiwan University College of Medicine) 2 (2) (1998): 126–137; Good, "Metaphors for Life and Society in Health and Illness and the Biotechnical Embrace," presented at International Symposium, Health Illness, Bologna, Italy, 1998. Also Good et al., "Medicine on the Edge: Conversations with Oncologists," in *Technoscientific Imaginaries: Conversations, Profiles and Memoirs*, ed. George Marcus (Chicago: University of Chicago Press, 1995), 129–152.

[4]Dr. Amayo, in conversation with the author, February 1997.

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[5]A. O. Obel et al., "Acquired Immunodeficiency Syndrome in an African," *East African Medical Journal* 61 (9) (1994): 724–726.

[6]See James M'Imunya Machoki, "Moral and Ethical Dilemmas in Medical Training," paper presented at the conference on East African Health and Social Change sponsored by the Department of Social Medicine, Harvard Medical School, 15 April 1999; WHO/UNAIDS, "Kenya Epidemiological Fact Sheet on HIV/AIDS and Sexually Transmitted Diseases" <http://www.who.int/emc-hiv/fact_sheets> (1997) and "AIDS Epidemic Update Fact Sheet," <http://www.who.int/emc-hiv/fact_sheets> (December 1998).

[7]C. F. Gilks et al., "HIV-1 Related Disease in a Hospital in Nairobi," *Journal of Acquired Immune Deficiency Syndromes and Human Retrovirology* 18 (3) (1998): 234–240.

[8]Machoki, "Moral and Ethical Dilemmas in Medical Training"; M. Temmerman et al., "Maternal HIV-1 Infection and Pregnancy Outcome," *Obstetrics & Gynecology* 83 (1994): 495–501; WHO/UNAIDS, "Kenya Epidemiological Fact Sheet on HIV/AIDS and Sexually Transmitted Diseases," and "AIDS Epidemic Update Fact Sheet."

[9]Dr. Amayo, in conversation with the author, February 1997.

[10]Ibid.

[11]Ibid.

[12]Ibid.

[13]Ibid.

[14]Machoki, "Moral and Ethical Dilemmas in Medical Training."

[15]Ibid.

[16]See Esther Mwaikambo, "The Culture of Medicine and Moral Dilemmas of Disclosure," paper presented at the Conference on East African Health and Social Change sponsored by the Department of Social Medicine, Harvard Medical School, 15 April 1999.

[17]The phrase "political economy of hope" comes from Mary-Jo DelVecchio Good et al., "American Oncology and the Discourse on Hope," *Culture, Medicine and Psychiatry* 14 (1) (1990): 59–79.

[18]John Iliffe, *African Doctors: A History of the Modern Profession* (New York: Cambridge University Press, 1998), 245.

[19]Ibid., 241.

[20]See Erastus Amayo, "Doing Good: Is It Possible with the HIV/AIDS Pandemic?" paper presented at the Conference on East African Health and Social Change sponsored by the Department of Social Medicine, Harvard Medical School, 15 April 1999; Machoki, "Moral and Ethical Dilemmas in Medical Training"; Mwaikambo, "The Culture of Medicine and Moral Dilemmas of Disclosure."

[21]See "Drugs for AIDS in Africa," *New York Times,* 23 August 1999.

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[22]See Iliffe, *African Doctors: A History of the Modern Profession,* for a detailed history of the profession in Uganda, Kenya, and Tanzania.

[23]The economic consequences of HIV/AIDS affect private business as well as public institutions because adults in their prime (both in their careers and as parents) are afflicted. See Wil Haygood, "AIDS and the African: Africans and Americans," *Boston Globe,* 13 October 1999, A1, A17.

[24]Mary-Jo DelVecchio Good, "Metaphors for Life and Society in Health and Illness," presentation at International Symposium on Health/Illness, Bologna, Italy, 26 October 1998. Good, *American Medicine: The Quest for Competence*; Good, "Cultural Studies of Biomedicine." Also Good et al., "American Oncology and the Discourse on Hope"; Good et al., "Medicine on the Edge: Conversations with Oncologists"; Mary-Jo DelVecchio Good et al., "Oncology and Narrative Time," *Social Science and Medicine* 38 (6) (1994): 855–862.

[25]Good et al., "American Oncology and the Discourse of Hope"; Good, *American Medicine: The Quest for Competence.*

[26]Michael Zinner, lecture to HST 930 class, Harvard Medical School, 7 November 1996.

[27]"Hope for Sale: Business Thrives on Unproven Care, Leaving Science Behind," *New York Times,* 3 October 1999.

[28]Dr. William Peters, Duke University Bone Marrow Transplantation Program, New Orleans Hearing of the Federal Insurance Commission, 5 December 1994.

[29]American Society of Clinical Oncology's web site (http://www.asco.org), April 1999 document on BMT clinical trials with breast cancer patients.

[30]See "In Tests of a Desperate Remedy, No Clear Results," *New York Times,* 16 April 1999, A1, A16; "Marrow Transplants Falling Short of Miracle," *Boston Globe,* 3 April 1999, A1.

[31]Lucy Muchiri, "Ethical Issues and Gender Inequities in Patient Care in Kenya," paper presented at the Conference on East African Health and Social Change sponsored by the Department of Social Medicine, Harvard Medical School, 15 April 1999; Mwaikambo, "The Culture of Medicine and Moral Dilemmas of Disclosure."

[32]David Mechanic, *Inescapable Decisions: The Imperatives of Health Reform* (New Brunswick, N.J.: Transaction Publishers, 1994).

[33]See "Drugs for AIDS in Africa" *New York Times,* 23 August 1999.

[34]It is important to note that the vast majority of Kenyan and Tanzanian physicians earn high salaries compared to their compatriots, and they live well at the top of the hierarchy of professionals, perhaps making the problem of limited resources for patients even more problematic and morally laden for some physicians.

[35]Machoki, "Moral and Ethical Dilemmas in Medical Training"; Muchiri, "Ethical Issues and Gender Inequities in Patient Care in Kenya"; Mwaikambo, "The Culture of Medicine and Moral Dilemmas of Disclosure"; Amayo, "Doing Good: Is it Possible with the HIV/AIDS Pandemic?"

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Nicholas A. Christakis

Prognostication and Bioethics

A SOCIAL SCIENTIFIC CRITIQUE of the field of bioethics can occur on at least two levels. The first involves the use of social-science theory to destabilize some of the assumptions underlying bioethics—for example, by arguing that ethics are socially contingent or culturally relative. The second involves the use of empirical social-science methods and findings to show how bioethical concerns play out in real situations or how ethical decisions are shaped by real behaviors and beliefs—a sort of "thick description" of bioethical decision making.[1] Using conceptual and empirical work on the problem of prognostication in medicine, and drawing on a multi-year research project of mine on this topic, I intend to do the latter here. My research involved numerous complementary studies that included mail surveys, psychological experiments, cohort studies, interviews, content analysis of texts, and participant observation—all directed at understanding how and why physicians do and do not prognosticate.[2]

Patients expect physicians to prognosticate in a fashion that is simultaneously—yet impossibly—honest, accurate, and optimistic.[3] Consequently, physicians find themselves in a situation fraught with "sociological ambivalence," that is, a situation that embodies contradictory demands placed on the occupants of a particular social role.[4] This social-structural ambivalence can in turn result in an intrapersonal, psychological ambivalence. Partly as a result of this ambivalence, physicians find

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prognostication, particularly about the end of life, to be troubling and stressful, and they employ approaches to cope with this stress. One is simply to avoid prognostication altogether; but physicians also adopt other compensatory behaviors, attitudes, and even ideological commitments when it comes to prognostication.

The avoidance of prognosis in medicine is quite thoroughgoing. Despite being a fundamental and important aspect of medical care, prognosis is virtually absent from medical education, medical texts, medical research, and patient care.[5] The relative absence of prognosis in modern medical thought and practice certainly cannot be explained by an absence of patient need or interest, however. Indeed, when patients are sick, their interest in diagnosis and therapy is often secondary to their interest in prognosis.[6] The avoidance of prognosis by physicians, it turns out, is neither accidental nor incidental, for there are powerful norms in the medical profession militating against both the development and the communication of prognoses. Physicians are socialized to avoid prognostication.

Remarkably, physicians tend to avoid two distinct elements of prognostication: foreseeing and foretelling. *Foreseeing* is a physician's inward, cognitive estimate about the future course of a patient's illness, and *foretelling* is the physician's outward communication of that estimate to the patient. There are several reasons that physicians avoid prognostication, including the objective difficulty of prognostication, the uncertainty and error inherent in it, the consequential nature of such error for the patient's care and the physician's reputation, the dependence of prognosis on social factors that physicians consider to be "soft," and the troublesome emotions prognosis can evoke for patients and physicians alike. Finally, physicians avoid prognostication because of a complementary relationship between therapy and prognosis in both the theoretical and the practical consideration given to disease; when therapy is available, as it usually is nowadays, prognosis is avoided.[7]

Prognostication in medicine raises questions quite beyond whether and how prognoses are developed or communicated. It also raises questions about certain ethical and moral aspects of physicians' practice. Both the avoidance of prognostication and

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certain related attitudes and practices have important implications for the theory and reality of a wide variety of bioethical decisions. Pertinently, physicians respond to the challenge of prognostication in a host of ways that have magical or religious overtones not generally expected in biomedical contexts. Here, I will examine some of the implications for bioethical decision making of the role prognosis plays in medical care. I will consider in particular detail one aspect of physicians' attitudes toward prognosis: namely, their belief in the self-fulfilling prophecy. In so doing, I hope to illustrate how social-science research on medical care can, and should, inform bioethical decisions and bioethical analysis. And I will argue that a clear understanding of the role of prognosis in medicine in turn supports the notion that prognostication itself is a deeply moral aspect of the physician's social role.

PHYSICIANS' BELIEFS ABOUT THE SELF-FULFILLING PROPHECY

Physicians do not merely find prognosis stressful and worthy of neglect; they also find it dreadful. This dread primarily arises from two sources, both of which have moral and ethical implications. First, prognosis is broadly identified with death in medical care. When physicians predict mortality, they are struggling with their role in forestalling or hastening death, and they unavoidably confront their relationship both to the individual patient's death and to death in general. To the extent that prognosis is linked with death, prognostication is necessarily mysterious and dangerous, and, therefore, dreaded. Second, physicians believe that predictions can affect outcomes through a kind of "self-fulfilling prophecy."[8] The self-fulfilling prophecy is a complex phenomenon, and, among other things, analysis of physicians' attitudes and behaviors in this area demonstrates a difference between *positive self-fulfilling prophecy,* which refers to favorable predictions that cause corresponding favorable outcomes, and *negative self-fulfilling prophecy,* which refers to unfavorable predictions that cause corresponding unfavorable outcomes.

Beliefs about the self-fulfilling prophecy are illustrative of a broader class of nonrational beliefs that are evoked by and

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supported by the necessity of prognostication—for prediction evokes both magical and religious sentiments in physicians. This is not unexpected, since both magic and religion are fundamental ways of coping with the strain posed by the limits of human ability and of science, especially in the face of death. The combination of high uncertainty, high stakes, and high emotional interests in medicine in general—and in prognostication in particular—produces a situation strongly conducive to magical and religious ways of thinking.[9] Nevertheless, physicians' belief in the self-fulfilling prophecy and their ideas about how it works are intriguing—and consequential for bioethical decision making—because they are found in a population of professionals who are ostensibly immune from such seemingly nonrational thinking and who are committed to, and trained for, a positivistic, biomedical perspective on illness and medicine. The transcendent outcomes that preoccupy medical care, the malleability, importance, and meaningfulness of these outcomes, and the interrelationship between technique and affect in medicine combine to provide fertile terrain for the emergence of such thinking.

Sociologist Robert K. Merton opens his classic essay on the self-fulfilling prophecy by citing a sociological theorem attributed to W. I. Thomas: "If men define situations as real, they are real in their consequences."[10] Predictions about a given situation are not only an integral part of the situation but also, more important, affect current behavior and subsequent outcomes. In affording an opportunity for self-fulfilling prophecy, social systems are unique. People can act on their predictions about the future in order to make the predictions come to pass. This effectiveness of predictions about the future is one of the main ways that social systems differ from physical ones—that is, they are *purposeful* rather than either *deterministic* or *stochastic*.[11] And it is one of the main reasons prognosis in medicine has both metaphysical significance and ethical implications: the effectiveness of prediction gives physicians greater clinical power and greater ethical obligations.

Prediction is effective on two levels. It may affect *present behavior* as a consequence of its articulation, and it may affect *future outcomes* through the change in behavior. These two

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effects are in turn enhanced by the conscious knowledge among actors that prediction has these consequences. People may in fact use predictions as a deliberate means to alter the future. In other words, it is the belief that predictions *can* alter the future (as well as beliefs about *how* predictions alter the future), more than the content of the predictions themselves, that is essential to the effectiveness of prediction. If people simply had impressions of what the future held (whether accurate or inaccurate) but did not believe that these impressions should or could influence the present or the future, then prediction would not have as much influence as it does. Moreover, people may believe in the self-fulfilling prophecy and act accordingly regardless of whether, in fact, the self-fulfilling prophecy "really works." While, for example, in medicine there is some evidence that predictions actually do contribute to outcomes, the key point is that even if they did not, the majority of doctors *believe* that predictions can cause outcomes.[12]

Physicians identify three mechanisms by which the self-fulfilling prophecy works. The first mechanism is to affect *patients'* attitudes, behaviors, and physiology. For example, physicians believe that predictions can make patients anxious or depressed and so affect outcomes, can influence patients' compliance with treatment and so affect outcomes, and can modify immunological or cardiovascular parameters and so affect outcomes. The second mechanism is to affect *physicians'* attitudes and behavior. For example, a prediction of an unfavorable outcome can cause a physician to become neglectful, and so result in the unfavorable outcome that was predicted. Or, a prediction that a critically ill patient will die can result in the withdrawal of life support and so cause the predicted outcome. The third, and most provocative, mechanism is that physicians believe that the self-fulfilling prophecy can work through direct, quasi-magical means: a prediction is made, and even if it is not revealed to the patient, it can cause something to happen in a word-made-flesh sort of way.[13]

That physicians believe that their predictions may be effective heightens their sense of responsibility for patient outcomes—whether a prognosis is made or not. The negative self-fulfilling prophecy raises the frightening prospect that physicians might,

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through the formulation and articulation of a prognosis, however accurate clinically or probabilistically, harm, or even kill, their patients. The belief in the negative self-fulfilling prophecy consequently places a powerful constraint on both formulating and communicating unfavorable predictions. The positive self-fulfilling prophecy is only slightly less problematic. The belief in the positive self-fulfilling prophecy raises the unsettling prospect that physicians might be expected to cause whatever favorable outcome they might predict. In other words, patients might once again hold physicians responsible for the outcome. Favorable predictions—whether volunteered by physicians or elicited by patients—considerably increase the onus on physicians.

The effectiveness of prognosis and the responsibility for outcomes it engenders cause physicians to believe that it is dangerous to make prognoses. The danger of prognosis is compounded, however, by the quasi-magical nature of the possible direct action of the self-fulfilling prophecy. The prospect that predictions might fulfill themselves in a quasi-magical way makes them all the more dangerous in that, if they are effective in a non-logico-rational way, then they are that much harder to understand and to control. Prognoses might "take on a life of their own." Physicians are much less threatened by the prospect that a prognosis might lead to changes in a patient's behavior that then might lead to a fulfillment of the prediction—a mechanism that makes logical sense—than they are threatened by the possibility that the prognosis itself, directly and obscurely, might lead to its own fulfillment. Indeed, the three mechanisms of effectiveness of the self-fulfilling prophecy identified above may be ordered from least to most dangerous as follows: the effect that predictions have on patients is less threatening than the effect predictions have on physicians, which in turn is less threatening than the quasi-magical effect of predictions. This order reflects a gradient in which the physician's responsibility for the patient's outcome steadily increases. It is one thing for physicians' prognoses to affect patients and thus outcomes; it is another for the prognoses to affect physicians themselves and thus outcomes; and it is quite another still for the prognoses to directly affect (and effect) the outcomes themselves.

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The facts that physicians believe in the self-fulfilling prophecy, that this belief is widespread, and that the self-fulfilling prophecy works in multiple ways are deeply consequential. Physicians act with the hope and fear that their predictions will shape patient outcomes. This set of beliefs affects how physicians interact with patients and how they view their work; consequently, it can affect both how abstract bioethical problems are analyzed and how actual, ethically relevant decisions are made.

Physicians believe that articulating a prognosis may be a deliberate way to control patients' behavior. This is indeed one of the main ways that the self-fulfilling prophecy is believed to work, and physicians often consciously choose to articulate prognoses in order, for example, to achieve the perceived beneficial effects of improved patient compliance or better outcome. The beliefs about the self-fulfilling prophecy and its modes of action also affect how and what physicians communicate to patients. The classical reason offered by physicians for not communicating bad news to patients is a desire to "protect" the patient. Over the last few decades, this perspective has come under withering criticism, especially in the bioethics literature, as being paternalistic and self-serving. But the prohibition against articulating unfavorable prognoses may also result from the conscious or subconscious fear that the unfavorable prognosis might have an effect via the self-fulfilling prophecy. Indeed, the aversion to articulating an unfavorable prognosis within earshot of the patient can be construed as a form of "sympathetic taboo" or "negative magic."[14] This observation helps explain both the withholding of information from patients and the widespread practice of the physician giving different information to the patient and to the patient's family. Although these communicative behaviors are in part a product of the difficulties and unpleasantness physicians encounter when sharing bad news with patients, they also reflect a desire to avoid contributing to a downward trajectory in the patient's illness through a self-fulfilling prophecy. Physicians do not wish to be responsible for patients' deaths. The consideration given to the ethics of communication between doctors and patients rarely, to my knowledge, acknowledges the fact that

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physicians may fear that their statements might cause outcomes.

The belief in the self-fulfilling prophecy also strongly contributes to what may be called the "ritualization of optimism" in medical prognostication.[15] Insofar as physicians believe that favorable predictions can cause favorable outcomes, they quite naturally try to "shade" their prognoses to the optimistic end of the continuum; they favor demonstrably positive ways of thinking about and interacting with their patients regarding their prognosis and their treatment; and they choose to say nothing, if possible, rather than offer an unfavorable prediction. Moreover, they have fewer reservations about articulating a favorable prognosis, if appropriate, not only because this enhances their feelings of professional effectiveness and relieves the patient's anxiety, but also because they believe that such an articulation actually serves therapeutic objectives and helps the patient.

Most generally, however, the belief in the self-fulfilling prophecy supports the norm that physicians should avoid prognosticating altogether. Because the self-fulfilling prophecy makes prognostication "dangerous," physicians often have much to lose by making predictions. If physicians did not believe in the self-fulfilling prophecy, they would be much more willing to make and state their predictions. The suppression of prognostic information in clinical care, however, impoverishes the interaction between patients and doctors and, especially since such information is often critical to ethically tinged decisions, compromises the ability of the patient (and the doctor) to make the best such decisions. Indeed, as we shall see, the avoidance of prognosis can itself be configured as a moral issue.

SOME ILLUSTRATIONS OF THE ROLE OF PROGNOSIS IN BIOETHICAL DECISIONS

Physicians' beliefs and practices with respect to prognostication in general and the self-fulfilling prophecy in particular have important implications for the ethical analysis of clinical decision making and also for the moral standing of doctors. Prognostication is in fact a major underpinning for many bio-

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ethical decisions, a fact that is typically unappreciated in the theoretical (and often the practical) consideration given to such decisions. For example, bioethical reasoning about the withdrawal of life support often proceeds as follows: The patient is going to die. Life support is of no further benefit. Life support may be harming the patient. Should we withdraw life support? This type of reasoning often neglects such questions as: How do we know the patient is going to die? How do we know life support is of no further benefit? Who is authorized to make these predictions? What if they are wrong? What if factors outside the patient's case influence the predictions? What if the predictions contribute to the outcome and change the "reality" of the situation? Analogously, much of the current debate in the ethics of physician-assisted suicide in patients who are irremediably terminally ill has focused on the ethical and legal aspects of doctors' engagement in such behavior, and has unfortunately generally taken for granted that doctors are willing and able to predict when a patient will die.[16] Prognostication is, indeed, the fundamental and essential basis for a determination of "futility," a relatively new doctrine whereby physicians are not obligated to provide care that they deem futile to critically ill patients.[17] This doctrine is being increasingly invoked to justify the withholding or withdrawal of life support from patients who are being harmed by it; in rare cases, it is invoked to withdraw life support over family objections. Futility is a fundamental assertion about the intractability of the patient's disease or about the impotence of the doctor's treatment to alter the course. Both are prognostic statements. Yet the prognostic aspects—in both theory and practice—are rarely explicitly acknowledged. Moreover, the key issues of how futility is determined and by whom, as well as its inherently self-fulfilling-prophecy-like nature, are often neglected.

Prognostication is a core element not only in bioethical decisions at the end of life, but also in numerous other areas. In organ transplantation, for example, a key (though not the only) component of allocation decisions is the "greatest benefit criterion," the standard whereby organs are allocated according to who stands to gain the most from the transplant and who has the least chance of rejecting it immunologically—which are

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essentially prognostic assessments. To the extent that organ allocation takes place depending on the likely success of the medical intervention, prognosis is an essential element of the ethical decision making. Indeed, organ allocation typifies a broader type of prognostically informed ethical concern, namely the allocation of scarce resources—whether ICU beds, blood products, or physician time.

Another area where prognosis is important, and is likely to be increasingly so, is in the ethical analysis of the use of genetic tests. To date, the ethical analysis of genetic testing has generally focused on the "ownership" of such information, the problems raised by revelation of such confidential information (e.g., for patients' insurability), or the threats such testing poses to our conception of collective risk and community. Yet the prognostic aspects of these tests raise special ethical questions—especially given the strong evocation of self-fulfilling prophecy that a test of one's genes generates—which might temper physicians' ardor for communicating genetic information. On another level, however, the use of genetic information for prognostic purposes will likely be more palatable for physicians than the current clinical bases for prognosis. The reason is that the genetic information will appear to be biologically preordained, scientifically fixed, unsusceptible to individual or social influences, and unmodifiable by physicians. Physicians will therefore probably feel more comfortable telling a patient with a gene associated with lung cancer that he is at increased risk for lung cancer—or even that he *will* develop cancer—than they will feel telling a patient who smokes that he will develop lung cancer, even if the risks are mathematically identical. Moreover, physicians may feel that genetic prognostication is less prone to error. The perception that genetics is a so very fundamental cause of events will help physicians to feel less responsible for both the prediction made and the outcome observed. Thus, many of the reasons that act to restrain physician prognostication will likely be less prominent when genes underlie the prognosis. Nevertheless, the use of genetic information in prognosis will heighten concerns about the role of individual destiny, concerns that may readily assume existential or religious overtones.

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With respect to the basic ethical concept of patient autonomy, which is the notion that patients should be respected as persons and thus allowed to determine their own care, the accuracy and quality of the information given to patients to allow them to do so and the feasibility of developing such information are rarely examined. Much of the time, patients' decisions specifically depend on prognostic assessments, and often the quality of prognostic information they are given is poor. Many ethical decisions that arise from the obligation to respect patient autonomy, ranging from so-called Advance Directives to informed consent, involve a sort of "hypothetical prognosis" in which physicians describe various possible scenarios that patients might experience in the future. Advance Directives are documents patients complete in which they express their wishes with respect to life support should they become both critically ill and unable to speak for themselves.[18] Ideally, these discussions are initiated by physicians and guided by them.[19] But in order to elicit the patient's preferences, the physician must first predict various possible outcomes. Informed consent is the expressed, uncoerced willingness of patients or research subjects to undergo a medical intervention about which they have adequate information, predominantly through a disclosure by physicians of risks and consequences.[20] During the informed consent process, the physician characterizes the proposed interventions by providing descriptions of possible outcomes of both the intervention and the alternatives, along with possible side effects of each. Thus, every time doctors or researchers obtain consent from a patient to administer a treatment or to conduct research, they are using prognosis. The extent to which the doctor is willing and able to make accurate predictions is therefore a very important factor in both advance directives and informed consent, and it ought to be an important factor both in terms of the ethical analysis of such decision making and in terms of the behaviors physicians exhibit when engaged in such decisions.

The analysis of bioethical concerns cannot be separated from the specific social context in which both the theory and the reality of these dilemmas emerge.[21] Numerous factors influence whether and how physicians develop and communicate prognoses, and these factors would need to be accounted for in both

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making and analyzing the various types of ethical decisions outlined above. What if doctors are systematically over-optimistic in their predictions of benefit from life-support technology and therefore overestimate its utility in their discussions with patients or in their actions on patients' behalf? What if doctors refuse to make predictions? What if accurate prediction is not possible? What if doctors' biases or behaviors in prognosis make it difficult for both them and their patients to make the most ethical decisions? What if predictions affect outcomes and so modify the basis for the ethical decision, even as it is being made? Surely the role of such questions cannot be ignored when considering the right thing to do in clinical decisions that have ethical dimensions. The notion that physicians have strong preferences and indeed nonrational beliefs (of one sort or another) when it comes to prognosis throws into question the extent to which prognostically relevant ethical decisions can be made or examined without also considering such "social" factors.

THE MORAL DUTY OF PROGNOSTICATION

Though the role of the physician has become progressively more secularized in American society, death itself—which remains a prominent focus of physicians' ministrations—has retained its mystical and religious properties. To the extent that prognosis is concerned with death, the act of prognostication cannot avoid highlighting the ineradicably nonsecular nature of healing. This aspect of prediction in modern medicine is only augmented by the dangerous, effective, or even quasi-magical properties that physicians believe it has.

A view of life that casts events as either random or predetermined makes the world uncontrollable, experience meaningless, and the events amoral. But in an indeterministic world—one in which at least some elements of the future can be purposefully realized—the future and statements about it are controllable, meaningful, and moral. In its ability to induce emotions and change behaviors, in its (at times self-fulfilling) effect on outcomes, and in its evocation of magic (and religion), prognosis resembles prophecy and, as such, casts the physician in the role

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of prophet. Elsewhere, I have invoked these analogies for three reasons.[22] First, they shed light on aspects of the neglected prognostic role of physicians. Second, they clarify an archetypical social relation—one not restricted to medical contexts—between a "prophet" and a "supplicant." And third, the resemblance between prognosis and prophecy highlights the moral and ethical dimensions of prognosis.

As a form of prophecy, prognosis is morally, and not merely biologically or even socially, encoded. Because prediction can affect both patients' and physicians' behaviors, and because it can affect patients' outcomes, it suggests that physicians have an important responsibility when they prognosticate. Physicians have an obligation to be aware of the ways prognosis informs their ethical decisions and an obligation to prognosticate as accurately and empathetically as possible. That is, there is not only a moral duty *in* prognostication, but also a moral duty *to* prognosticate. Thus, the avoidance of prognosis that is prevalent in medical care represents the shirking not only of a clinical but also of a moral responsibility by physicians, a responsibility that pertains both to individual physicians and to the profession as a whole.

An important source of this responsibility is that prognosis often involves transcendent concerns. Death is a focus of ethical, religious, existential, and moral attention whenever and however it occurs. Similarly, the existence and remission of suffering are also foci of moral examination. Did the patient do anything to bring about the suffering? What sort of life has the dying person led? What are the implications of an awareness of death? What meaning does the individual see in his or her death?[23] The salience of these questions is heightened by the fact that physicians often can influence the course of illness and the manner of death. This raises still further moral questions. What is the meaning of this influence, and how might it best be exercised? What sorts of actions should the patient or doctor engage in to modify the course of the illness? Insofar as prognostication is linked with suffering and death, and insofar as it influences these thoughts and actions, it is inextricably connected to the most consequential and meaningful sorts of moral concerns.

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The moral obligation to prognosticate is further supported by the existence of an asymmetry in the power and knowledge of the patient and physician. The patient is sick, perhaps with a terminal illness, and the doctor has technical knowledge and therapy that the patient is seeking. The physical and emotional vulnerability of such seriously ill patients is extraordinary and, coupled with the professional authority of the physician, suffuses the entire clinical encounter with the strongest possible obligations. As a result of this asymmetry, and of the trust patients put in them, physicians hold power over patients—and, literally and metaphorically, over their future. The fact that patients are so dependent on their doctors creates prognostic obligations no less than it creates diagnostic and therapeutic ones. The burden of prediction more justly falls to the one who is better able—by virtue of expert training, lack of vulnerability, and claims to authority—to bear it.[24]

In order to enhance the use of prognosis in clinical practice (in the sense of both foreseeing and foretelling) and to meet the duty to prognosticate, certain obstacles clearly must be overcome. Patients do not always want prognostic information, and physicians will have to be sensitive to this. Prognostic information can be harmful to patients. Physicians are generally needlessly inaccurate in the prognoses they develop and communicate.[25] Information regarding prognosis in educational venues and materials is currently minimal. And physicians resist generating prognostic information. These practical obstacles to prognostication, however, do not subvert the moral obligation to prognosticate.

At the level of the individual physician, there are several opportunities for improvement. Physicians should make efforts to improve both their foreseeing and their foretelling of the future. Inwardly, they should strive to more formally and more routinely incorporate prognostic thinking into their management, much as they currently incorporate the patient's symptoms or test results. In this vein, physicians might keep mental track of the accuracy of their prognoses, much as they keep track of the accuracy of their diagnostic and therapeutic decisions. If physicians were to begin a process of self-calibration in this respect, their accuracy and confidence in prognosis

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might both increase. Physicians might also make greater efforts to avail themselves of prognostic resources that do exist because information is increasingly becoming available on how to formulate and evaluate prognostic information in many clinical situations.[26] Greater attention to foretelling is also clearly in order. Physicians have a very hard time communicating prognoses, and they do so poorly. Yet good resources to enhance their communication exist, and poor performance need not be tolerated.[27] In any case, no matter how difficult it may be for physicians to foretell the future, physicians can make more of an effort to foresee it. To the extent that they are able to overcome their aversion to prognosis or their propensity for error in prognosis, physicians may enhance the factual basis for numerous ethical decisions, and so enhance the specifically ethical quality of these decisions.

However sympathetic we might be to individual physicians who avoid prognosis or who make advertent or inadvertent errors in prognosis, we need not be so forgiving of the profession as a whole. As Alvan Feinstein, an authority on ways to enhance the science of clinical care, noted in 1983: "The omission of prediction from the major goals of basic medical science has impoverished the intellectual content of clinical work, since a modern clinician's main challenge in the care of patients is to make predictions."[28] The avoidance of prognosis at the professional level is particularly deplorable since at this level there is no *interpersonal* justification for the absence. Research and education regarding prognosis cannot by any means harm patients, nor can coverage of prognosis in textbooks and journals. From a policy or ethical perspective, whatever allowance we might accord to individual physicians for their avoidance of prognostication, there should be none at the professional level.

Despite the arguments that prognosis is a moral duty, it is also clear from the analysis of physicians' attitudes and behaviors with respect to prognosis that these attitudes and behaviors are deeply embedded in the practice of medicine. Consequently, the practical and ethical concerns that prognosis raises cannot be addressed simply by the invocation of ethical principles. It is not possible to ignore the phenomenological reality of the physician's social and moral predicament in prognosis. The

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social scientific study of the role of prognosis in medicine illuminates the rich complexity of this phenomenon, a complexity that is not merely ethical.

ENDNOTES

[1]Noteworthy examples of such work include: Renée R. Anspach, *Deciding Who Lives: Fateful Choices in the Intensive-Care Nursery* (Berkeley: University of California Press, 1993); Charles L. Bosk, *"All God's Mistakes": Genetic Counseling in a Pediatric Hospital* (Chicago: University of Chicago Press, 1992); Renée C. Fox, *Experiment Perilous* (Boston: The Free Press, 1959); Renée C. Fox and Judith P. Swazey, *The Courage to Fail: A Social View of Organ Transplants and Dialysis,* 2d ed., rev. (Chicago: University of Chicago Press, 1978); Jonathan B. Imber, *Abortion and the Private Practice of Medicine* (New Haven, Conn.: Yale University Press, 1986); and Robert Zussman, *Intensive Care: Medical Ethics and the Medical Profession* (Chicago: University of Chicago Press, 1992).

[2]Nicholas A. Christakis, *Death Foretold: Prophecy and Prognosis in Medical Care* (Chicago: University of Chicago Press, 1999).

[3]Ibid., 90ff. See also Jean S. Kutner et al., "Information Needs in Terminal Illness," *Social Science and Medicine* 48 (1999): 1341–1352.

[4]Robert K. Merton and Elinor Barber, "Sociological Ambivalence," in Robert K. Merton, *Sociological Ambivalence and Other Essays* (New York: The Free Press, 1976), 8.

[5]Christakis, *Death Foretold.* See also Nicholas A. Christakis and Theodore J. Iwashyna, "Attitude and Self-Reported Practice Regarding Prognostication in a National Sample of Internists," *Archives of Internal Medicine* 158 (1998): 2389–2395.

[6]See, for example, Lesley F. Degner et al., "Information Needs and Decisional Preferences in Women with Breast Cancer," *Journal of the American Medical Association* 277 (1997): 1485–1492; Christina G. Blanchard et al., "Information and Decision-Making Preferences of Hospitalized Adult Cancer Patients," *Social Science and Medicine* 27 (1988): 1139–1145.

[7]Nicholas A. Christakis, "The Ellipsis of Prognosis in Modern Medical Thought," *Social Science and Medicine* 44 (1997): 301–315.

[8]Christakis, *Death Foretold,* 135–162.

[9]As social theorist Talcott Parsons has argued: "The health situation is a classic one of the combination of uncertainty and strong emotional interests which produce a situation of strain and is very frequently a prominent focus of magic. But the fact that the basic cultural tradition of modern medicine is science precludes outright magic, which is explicitly non-scientific." See Talcott Parsons, *The Social System* (New York: The Free Press, 1951), 469. This type of magical thinking about prediction is in keeping with other forms of "scien-

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tific magic" seen in medicine. See Renée C. Fox, "The Human Condition of Health Professionals," in Renée C. Fox, ed., *Essays in Medical Sociology: Journeys into the Field* (New Brunswick, N.J.: Transaction Books, 1988), 581, and Renée C. Fox, *The Sociology of Medicine* (Englewood Cliffs, N.J.: Prentice Hall, 1989), 198.

[10]Robert K. Merton, "The Self-Fulfilling Prophecy," in Robert K. Merton, *Social Theory and Social Structure* (New York: The Free Press, 1968), 475–490. See also Robert K. Merton, "The Thomas Theorem and the Matthew Effect," *Social Forces* 74 (1995): 379–422. For a broader consideration of the self-fulfilling prophecy, see Richard L. Henshel, "The Boundary of the Self-Fulfilling Prophecy and the Dilemma of Social Prediction," *The British Journal of Sociology* 33 (1982): 511–528.

[11]Regarding the issue of the purposefulness of social systems more generally, see Karl Popper, *The Open Universe: An Argument for Indeterminism* (London: Routledge, 1982).

[12]For example, one study found that, by one measure, 73 percent of physicians believed in positive and 61 percent in negative self-fulfilling prophecy. These beliefs were relatively homogeneously distributed among physicians. See Christakis, *Death Foretold,* 225.

[13]Christakis, *Death Foretold,* 144–150. By "quasi-magical" I mean that the effectiveness of prediction depends partly on rational, explainable mechanisms and also *simultaneously* on nonrational, inexplicable mechanisms.

[14]Marcel Mauss, *A General Theory of Magic,* trans. Robert Brain (New York: Norton, 1972). See also Stanley J. Reiser, "Words as Scalpels: Transmitting Evidence in the Clinical Dialogue," *Annals of Internal Medicine* 92 (1980): 837–842.

[15]This term was first used by Bronislaw Malinowski. See Bronislaw Malinowski, *Magic, Science and Religion* (Boston: Beacon Press, 1948), 70. It has been previously applied to medicine by Talcott Parsons and Renée Fox.

[16]Margaret A. Drickamer, Melinda A. Lee, and Linda Ganzini, "Practical Issues in Physician-Assisted Suicide," *Annals of Internal Medicine* 126 (1997): 146–151; Melinda A. Lee et al., "Legalizing Assisted Suicide—Views of Physicians in Oregon," *New England Journal of Medicine* 334 (1996): 310–315.

[17]Nancy S. Jecker and Lawrence J. Schneiderman, "Medical Futility: The Duty Not to Treat," *Cambridge Quarterly Healthcare Ethics* 2 (1993): 151–159; Lawrence J. Schneiderman and Nancy S. Jecker, "Futility in Practice," *Archives of Internal Medicine* 153 (1993): 437–441.

[18]Ben A. Rich, "Prospective Autonomy and Critical Interests: A Narrative Defense of the Moral Authority of Advance Directives," *Cambridge Quarterly of Healthcare Ethics* 6 (1997): 138–147; Steven H. Miles, Robert Koepp, and Eileen P. Weber, "Advance End-of-Life Treatment Planning: A Research Review," *Archives of Internal Medicine* 156 (1996): 1062–1068; Lawrence J. Schneiderman et al., "Effects of Offering Advance Directives on Medical Treatments and Costs," *Annals of Internal Medicine* 117 (1992): 599–606.

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[19]James A. Tulsky et al., "Opening the Black Box: How Do Physicians Communicate about Advance Directives?" *Annals of Internal Medicine* 129 (1998): 441–449.

[20]Ruth R. Faden and Tom L. Beauchamp, *A History and Theory of Informed Consent* (New York: Oxford University Press, 1986).

[21]See, for elaboration, Nicholas A. Christakis, "Ethics Are Local: Engaging Cross-Cultural Variation in the Ethics for Clinical Research," *Social Science and Medicine* 35 (1992): 1079–1091.

[22]Christakis, *Death Foretold,* 179–199.

[23]See Daniel Callahan, *The Troubled Dream of Life: In Search of a Peaceful Death* (New York: Simon and Schuster, 1993) and Arthur Kleinman, *The Illness Narratives: Suffering, Healing, and the Human Condition* (New York: Basic Books, 1988).

[24]A corollary of the asymmetry in power between patient and physician is that prognostication is open to venal manipulation by the physician for self-serving ends; it requires vigilance on the part of the doctor to avoid this.

[25]See, for example, Nicholas A. Christakis and Elizabeth B. Lamont, "The Extent and Determinants of Error in Physicians' Prognoses in Terminally Ill Patients: A Prospective Cohort Study," *British Medical Journal* (in press); Elizabeth B. Lamont and Nicholas A. Christakis, "Physicians' Preferences for Prognostic Disclosure to Terminally Ill Cancer Patients," unpublished manuscript.

[26]For illustrative reviews, see Nicholas A. Christakis and Greg A. Sachs, "The Role of Prognosis in Clinical Decision Making," *Journal of General Internal Medicine* 11 (1996): 422–425; James F. Fries and George B. Ehrlich, *Prognosis: Contemporary Outcomes of Disease* (Bowie, Md.: Charles Press, 1981); Charles M. Wattts and William A. Knaus, "The Case for Using Objective Scoring Systems to Predict Intensive Care Unit Outcome, *Critical Care Clinics* 10 (1994): 73–89; Michael Seneff and William A. Knaus, "Predicting Patient Outcome from Intensive Care: A Guide to APACHE, MPM, SAPS, PRISM, and Other Prognostic Scoring Systems," *Journal of Intensive Care Medicine* 5 (1990): 33–52.

[27]See, for example, Robert Buckman, *How to Break Bad News: A Guide for Health Care Professionals* (Baltimore, Md.: Johns Hopkins University Press, 1992).

[28]Alvan R. Feinstein, "An Additional Basic Science for Clinical Medicine I: The Constraining Fundamental Paradigms," *Annals of Internal Medicine* 99 (1983): 394.

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Norman Daniels, Bruce P. Kennedy, and Ichiro Kawachi

Why Justice is Good for Our Health: The Social Determinants of Health Inequalities

JUSTICE AND HEALTH INEQUALITIES

WE HAVE KNOWN for over 150 years that an individual's chances of life and death are patterned according to social class: the more affluent and educated people are, the longer and healthier their lives.[1] These patterns persist even when there is universal access to health care—a fact quite surprising to those who think financial access to medical services is the primary determinant of health status. In fact, recent cross-national evidence suggests that the greater the degree of socioeconomic inequality that exists within a society, the steeper the *gradient* of health inequality. As a result, middle-income groups in a less equal society will have worse health than comparable or even poorer groups in a society with greater equality. Of course, one cannot infer causation from correlation, but there are plausible hypotheses about pathways that link social inequalities to health. Even if more work remains to be done to clarify the exact mechanisms, it is not unreasonable to talk here about the social "determinants" of health.[2]

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When is an inequality in health status between different socioeconomic groups unjust?[3] An account of justice should help us determine which inequalities are unjust and which are tolerable. Many who are untroubled by some kinds of inequality are particularly troubled by health inequalities. They believe a socioeconomic inequality that otherwise seems just becomes unjust if it contributes to inequalities in health. But is every health inequality that results from unequally distributed social goods unjust? If there is an irreducible health gradient across socioeconomic groups, does that make the very existence of those inequalities unjust? Alternatively, are some health inequalities the result of acceptable trade-offs? Perhaps they are simply an unfortunate by-product of inequalities that work in other ways to help worse-off groups. For example, it is often claimed that permitting economic inequality provides incentives to work harder, thereby stimulating growth that will ultimately benefit the poorest groups. To whom must these trade-offs be acceptable if we are to consider them just? Are they acceptable only if they are part of a strategy aimed at moving the situation toward a more just arrangement? Does it matter in our judgments about justice exactly how social determinants produce inequalities in health status?

These are hard questions. Unfortunately, they have been almost completely ignored within the field of bioethics, as well as within ethics and political philosophy more generally. Bioethics has been quick to focus on exotic new medical technologies and how they might affect our lives. It has paid considerable attention to the doctor-patient relationship and how changes in the health-care system affect it. With some significant exceptions, it has not looked "upstream" from the point of delivery of medical services to the role of the health-care system in delivering improved population health. It has even more rarely looked further upstream to social arrangements that determine the health achievement of societies.[4]

This omission is quite striking, since a concern about "health equity" and its social determinants has emerged as an important consideration in the policies of several European countries over the last two decades.[5] The World Health Organization (WHO) has devoted increasing attention to inequalities in health

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status and the policies that cause or mitigate them. So have research initiatives, such as the Global Health Equity Initiative, funded by the Swedish International Development Agency and the Rockefeller Foundation.

In what follows, we attempt to fill this bioethical gap by addressing some of these questions about justice and health inequalities. Rather than canvass answers that might be extracted from various competing theories of justice, however, we shall work primarily within the framework of John Rawls's theory of "justice as fairness" and the extension one of us has made of it to health care, probing the resources of that theory to address these issues.[6] Our contention is that Rawls's (extended) theory provides, albeit unintentionally, a defensible account of how to distribute the social determinants of health fairly. If we are right, this unexpected application to a novel problem demonstrates a fruitful generalizability of the theory analogous to the extension in scope or power of a nonmoral theory, and permits us to think more systematically across the disciplines of public health, medicine, and political philosophy.

The theory of justice as fairness was formulated to specify terms of social cooperation that free and equal citizens can accept as fair. Specifically, it assures people of equal basic liberties, including equal access to political participation; guarantees a robust form of equal opportunity; and imposes significant constraints on inequalities. Together, these principles aim at meeting the "needs of free and equal citizens," a form of egalitarianism Rawls calls "democratic equality."[7] A crucial component of democratic equality is providing all with the social bases of self respect and a conviction that prospects in life are fair. As the empirical literature demonstrates, institutions conforming to these principles together focus on several crucial pathways through which many researchers believe inequality works to produce health inequality. Of course, this theory does not answer all of our questions about justice and health inequality, since there are some crucial points on which it is silent, but it does provide considerable guidance on central issues.

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SOCIAL DETERMINANTS OF HEALTH: SOME BASIC FINDINGS

There are four central findings in the literature on the social determinants of health, each of which has implications for an account of justice and health inequalities. First, the income/health gradients we observe are not the result of some fixed or determinate laws of economic development, but are influenced by policy choices. Second, the income/health gradients are not just the result of the deprivation of the poorest groups. Rather, a gradient in health operates across the whole socioeconomic spectrum within societies, such that the slope or steepness of the income/health gradient is affected by the degree of inequality in a society. Third, relative income or socioeconomic status (SES) is as important as, and may be more important than, the absolute level of income in determining health status, at least once societies have passed a certain threshold. Fourth, there are identifiable social and psychosocial pathways through which inequality produces its effects on health (and only modest support for "health selection," the claim that health status determines economic position).[8] These causal pathways are amenable to specific policy choices that should be guided by considerations of justice.

Cross-National Evidence on Health Inequalities

The pervasive finding that prosperity is related to health, whether measured at the level of nations or at the level of individuals, might lead one to the conclusion that these "income/health gradients" are inevitable. They might seem to reflect the natural ordering of societies along some fixed, idealized teleology of economic development. At the individual level, the gradient might appear to be the result of the natural selection of the most "fit" members within a society who are thus better able to garner socioeconomic advantage.

Despite the appeal and power of these ideas, they run counter to the evidence. Figure 1 shows the relationship between the wealth and health of nations as measured by per capita gross domestic product (GDPpc) and life expectancy. There is a clear association between GDPpc and life expectancy, but only up to

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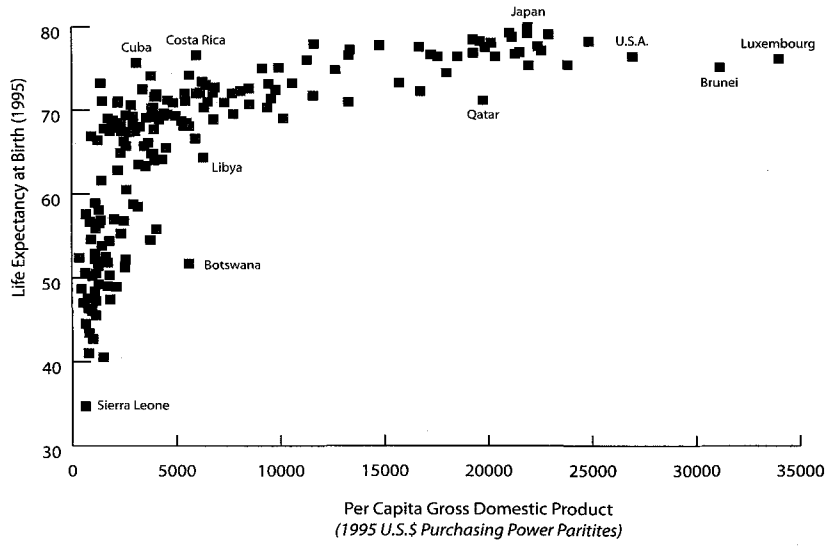
Figure 1: Relationship between country wealth and life expectancy



Source: United Nations Human Development Report Statistics, 1998.

a point. The relationship levels off beyond about $8,000–$10,000 GDPpc, with virtually no further gains in life expectancy.

This leveling effect is most apparent among the advanced industrial economies (see Figure 2), which largely account for the upper tail of the curve in Figure 1. The leveling of the relationship between wealth and health is true *within* individual countries as well.

Closer inspection of these two figures points out some startling discrepancies. Though Cuba and Iraq are equally poor (GDPpc about $3,100), life expectancy in Cuba exceeds that in Iraq by 17.2 years. The difference between the GDPpc for Costa Rica and the United States, for example, is enormous (about $21,000), yet Costa Rica's life expectancy exceeds that of the United States (76.6 versus 76.4). In fact, despite being one of the richest nations on the globe, the United States performs rather poorly on health indicators.

Taken together, these observations support the notion that the relationship between economic development and health is not fixed, and that the health achievement of nations is medi-

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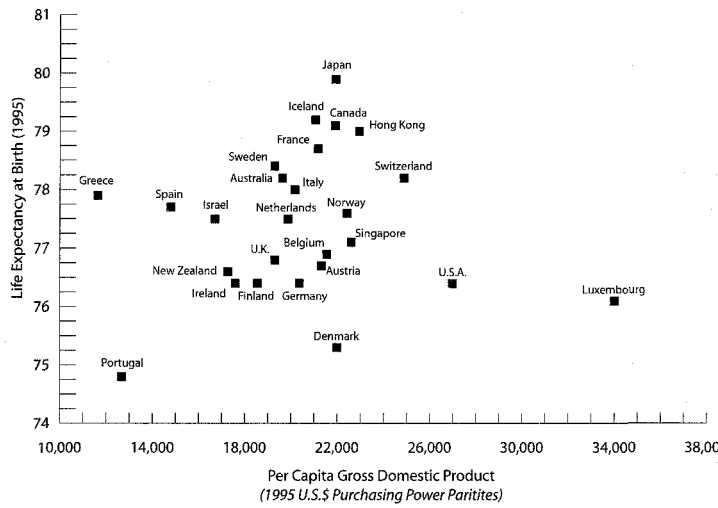
Figure 2: Per capita gross domestic product, 1995 U.S.$ purchasing-power parities



Source: United Nations Human Development Report Statistics, 1998.

ated by processes other than wealth. To account for the cross-national variations in health, it is apparent that other factors—such as culture, social organization, and government policies—are significantly involved in the determination of population health, and that variations in these factors may go some distance toward explaining the differences in health outcomes between nations.

If we are right that the health of nations does not reflect some inevitable natural order but that it reflects policy choices—or features of society that are amenable to change via policies—then we must ask which of these policies are just.

Individual Socioeconomic Status and Health

At the individual level, numerous studies have documented what has come to be known as the "socioeconomic gradient." On this gradient, each increment up the socioeconomic hierarchy is associated with improved health outcomes over the rung

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below.[9] It is important to observe that this relationship is not simply a contrast between the health of the rich and the poor but is observed across all levels of socioeconomic status. What is particularly notable about the SES gradient is that it does not appear to be explained by differences in access to health care. Steep gradients have been observed even among groups of individuals, such as British civil servants, with adequate access to health care, housing, and transport.[10]

Importantly, the steepness of the gradient varies substantially across societies. Some societies show a relatively shallow gradient in mortality across SES groups. Others, with comparable or even higher levels of economic development, show much steeper gradients in mortality rates across the socioeconomic hierarchy. The determining factor in the steepness of the gradient appears to be the extent of income inequality in a society. Thus, middle-income groups in a country with high income inequality may have lower health status than comparable or even poorer groups in a society with less income inequality. We find the same pattern within the United States when we examine state and metropolitan area variations in inequality and health outcomes.[11]

Relative Income and Health

The apparent connection between the distribution of income in a society and the level of health achievement of its members is a relatively recent finding.[12] Simply stated, it is not just the size of the economic pie but how the pie is shared that matters for population health. It is not the absolute deprivation associated with low economic development (lack of access to the basic material conditions necessary for health such as clean water, adequate nutrition and housing, and general sanitary living conditions) that explains health differences between developed nations, but the degree of *relative* deprivation within them. Relative deprivation refers not to a lack of the "goods" that are basic to survival, but rather to a lack of sources of self-respect that are deemed essential for full participation in society.

Numerous studies have provided support for the relative-income hypothesis, both between and within nations.[13] This finding helps to explain the anomalies highlighted in Figures 1

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and 2. Much of the variation in life expectancy for the wealthy countries in the upper tail of Figure 1 is explained by income distribution: countries with more equal income distributions, such as Sweden and Japan, have higher life expectancies than do countries such as the United States, regardless of GDPpc. Furthermore, countries with much lower GDPpc, such as Costa Rica, appear to be able to obtain their remarkably high life expectancy through a more equitable distribution of income.

Within the United States, income inequality accounts for about 25 percent of the between-state variance in age-adjusted mortality rates independent of state median income.[14] Moreover, the size of this relationship is not trivial. A recent study across U.S. metropolitan areas, rather than states, found that areas with high income inequality had an excess of death compared to areas of low inequality that was equivalent in magnitude to all deaths due to heart disease.[15]

While most of the evidence so far has been accumulated from cross-sectional data, time-trend data support similar conclusions. Widening income differentials in the United States and the United Kingdom appear to be related to a slowing down of life-expectancy improvements. In many of the poorest areas of the United Kingdom, mortality for younger age cohorts has actually increased during the same period that income inequality widened.[16] In the United States, states with the highest income inequality showed slower rates of life-expectancy improvement compared to states with more equitable income distributions between 1980 and 1990.[17]

As we noted above, income distribution appears to affect the health of populations by shifting the slope of the curve relating individual income to health. This can be clearly seen in Figure 3, where the prevalence of self-reported fair/poor health is higher (and the gradient steeper) in almost every income group for those living in states with the highest income inequality.[18] Nearly identical patterns have been found for individual mortality rates.[19]

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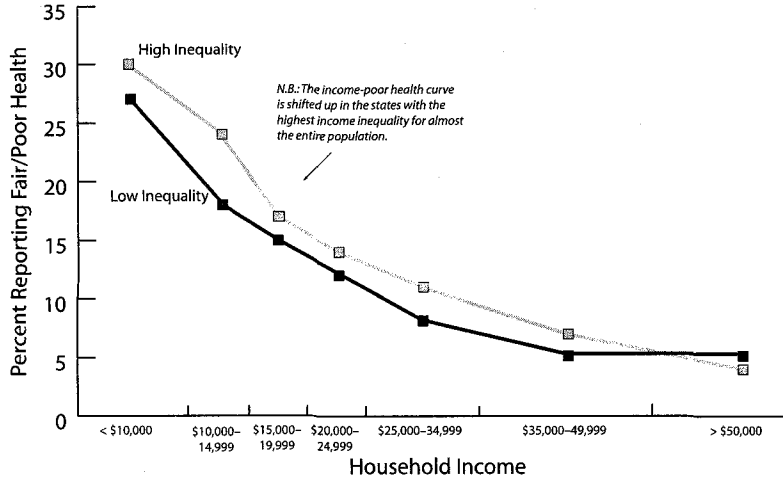
Figure 3: Self-related health and individual household income in the U.S.



Source: Ichiro Kawachi and Bruce P. Kennedy, "Income Inequality and Health: Pathways and Mechanisms," *Health Services Research* 34 (1999): 215–227.

Pathways Linking Social Inequalities to Health Inequalities

Our final contention is that there are plausible and identifiable pathways through which social inequalities produce inequalities in health. Some of these occur at the societal level, where income inequality creates a pattern for the distribution of social goods, such as public education, thereby affecting access to life opportunities—which are, in turn, strong determinants of health.

The evidence for these associations, while fairly new, is quite striking. In the United States, the most inegalitarian states with respect to income distribution invest less in public education, have larger uninsured populations, and spend less on social safety nets.[20] Differences in human capital investment, typically measured in terms of educational spending and (more important) educational outcomes, are particularly striking. Even when controlling for median income, income inequality explains about 40 percent of the between-state variation in the percentage of children in the fourth grade who fall below the basic reading level. Similarly strong associations are seen in the percentage of

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high-school dropout rates. It is quite evident from these data that educational opportunities for children in high income-inequality states are quite different from those in states with more egalitarian distributions.

Differential investment in human capital is also a strong predictor of health across nations. Indeed, one of the strongest predictors of life expectancy among developing countries is adult literacy, particularly the disparity between male and female adult literacy. For example, among the 125 developing countries with GDPpc less than $10,000, the difference between male and female literacy accounts for 40 percent of the variance in life expectancy after factoring out the effect of GDPpc. The fact that gender disparities in access to basic education drives the level of health achievement emphasizes further the role of broader social inequalities in patterning health inequalities. Indeed, in the United States, differences between the states in women's status—measured in terms of their economic autonomy and political participation—are strongly correlated with female mortality rates.[21]

These societal mechanisms are tightly linked to the political processes that influence government policy. One way that income inequality affects health and social welfare appears to be through its role in undermining civil society. Income inequality erodes social cohesion, as measured by levels of social mistrust and participation in civic organizations, both of which are features of civil society.[22] Lack of social cohesion is in turn reflected in significantly lower participation in political activity (e.g., voting, serving in local government, volunteering for political campaigns, etc.), thus undermining the responsiveness of government institutions in addressing the needs of the worst off in society. This is demonstrated by the human capital investment data presented earlier, but it is also reflected by the lack of investment in human security. States with the highest income inequality, and thus the lowest levels of social capital and political participation, are far less generous in the provision of social safety nets. For example, the correlation between social capital, as measured by low interpersonal trust, and the maximum welfare grant as a percent of state per capita income is –0.76.[23]

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How can the points we have highlighted from scientific literature on social determinants be integrated into our views about the moral acceptability of health inequalities? Historically, disciplinary boundaries have stood as an obstacle to an integrated perspective. The social-science and public-health literature sharpens our understanding of the causes of health inequalities, but it contains no systematic way to evaluate the overall fairness of those inequalities and the socioeconomic inequalities that produce them. The philosophical literature has produced theories aimed at evaluating socioeconomic inequalities, but it has tended to ignore health inequalities and their causes. To produce an integrated view, we shall need the resources of a more general theory of justice. We can better see the need for such a theory if we first examine an analysis of "health inequities" that has been developed within a policy-oriented public-health literature.

HEALTH INEQUALITIES AND INEQUITIES

When is a health inequality between two groups "inequitable"? This version of our earlier question about health inequalities and justice has been the focus of European and WHO efforts, as noted above. One initial answer that has been influential in the WHO programs is the claim, posited in writings by such researchers as Margaret Whitehead and Goran Dahlgren, that health inequalities count as inequities when they are *avoidable*, *unnecessary*, and *unfair*.[24] If we can agree on what is avoidable, unnecessary, and unfair—and if this analysis is correct—then we can agree on which inequalities are inequitable.

Age, gender, race, and ethnic differences in health status exist that are independent of socioeconomic differences, and they raise distinct questions about equity or justice. For example, should we view the lower life expectancy of men compared to women in developed countries as an inequity? If it is rooted in biological differences that we do not know how to overcome, then, according to this analysis, it is not avoidable and therefore not an inequity. This is not an idle controversy: taking average, rather than gender-differentiated, life expectancy in developed countries as a benchmark will yield different

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estimates of the degree of inequity women face in some developing countries. In any case, the analysis of inequity is here only as good as our understanding of what is avoidable or unnecessary.

The same point applies to judgments about fairness. Is the poorer health status of some social classes or ethnic groups that engage in heavy tobacco and alcohol use unfair? We may be inclined to say it is not unfair, provided that participation in the risky behaviors or their avoidance is truly voluntary. But if many people in a cultural group or class behave similarly, there may also be factors at work that reduce how voluntary their behavior is and how much responsibility we should ascribe to them for it.[25] The analysis thus leaves us with the unresolved complexity of these judgments about responsibility and, as a result, with disagreements about fairness (or avoidability).

The poor in many countries lack access to clean water, sanitation, adequate shelter, basic education, vaccinations, and prenatal and maternal care. As a result of some or all of these factors, there are infant mortality differences between these and richer groups. Since social policies could supply the missing determinants of infant health, the inequalities must be regarded as avoidable. Are these inequalities also unfair? Most of us would immediately think they are, perhaps from a view that policies that not only countenance but sustain poverty are unjust. Social policies that compound poverty with a lack of access to the determinants of health may be viewed as doubly unfair. Of course, libertarians would disagree. They would insist that what is merely unfortunate is not unfair; in their view, society has no obligation of justice (as opposed to charity) to provide the poor with what they are missing.

Many of us might be inclined to reject the libertarian view as in itself unjust because of the dramatic conflict it opens with our beliefs about poverty and our social obligations to meet people's basic needs. The problem becomes more complicated, however, when we remember one of the basic findings from the literature on social determinants: we cannot eliminate health inequalities simply by eliminating poverty. Health inequalities persist even in societies that provide the poor with access to all of the determinants of health noted above, and they persist as a gra-

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dient of health throughout the social hierarchy, not just between the very poorest groups and those above them.

Faced with this realization, many of us may have to reexamine what we believe about the justice of other sorts of socioeconomic inequalities. Unless we believe that all socioeconomic inequalities (or at least all inequalities we did not choose) are unjust—and very few embrace such a radically egalitarian view—then we must consider more carefully the problem posed by the health gradient and the fact that it is made steeper under more unequal social arrangements. Judgments about fairness—to which many, rightly or wrongly, feel confident in appealing when rejecting the libertarian position—give less guidance than perhaps had been expected in thinking about the broader issue of the social determinants of health inequalities. Indeed, we may even believe that some degree of socioeconomic inequality is unavoidable or even necessary, and therefore not unjust.

JUSTICE AS FAIRNESS AND HEALTH INEQUALITIES

One reason we develop general ethical theories, including theories of justice, is to provide a framework within which to resolve important disputes of the sort we have just raised about conflicting moral beliefs or intuitions. For example, in *A Theory of Justice* John Rawls sought to leverage the relatively broad liberal agreement on principles guaranteeing certain equal basic liberties into an agreement on a principle limiting socioeconomic inequalities—a matter on which liberals disagree considerably.[26] His strategy was to show that a social contract designed to be fair to free and equal people ("justice as [procedural] fairness") would not only justify the choice of those equal basic liberties but would also justify the choice of principles guaranteeing equal opportunity and limiting inequalities to those that work to make the worst-off groups fare as well as possible.

Our contention is that Rawls's account, though developed to answer this general question about social justice without specifically contending with issues of disease or health, turns out to provide useful principles for the just distribution of the social determinants of health. To simplify the construction of his

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theory, Rawls assumed his contractors would be fully functional over a normal life span—i.e., that no one would become ill or die prematurely.

This idealization itself provides a clue about how to extend this theory to the real world of illness and premature death. The goal of public health and medicine is to keep people as close as possible to the ideal of normal functioning, under reasonable resource constraints. (Resources are necessarily limited since maintaining health cannot be our only social good or goal.) Since the maintenance of normal functioning makes a limited but significant contribution to protecting the range of opportunities open to all individuals, it is plausible to see a principle guaranteeing equality of opportunity satisfying the condition of fairness as the appropriate principle to govern the distribution of health care, broadly construed to include primary and secondary preventive health as well as medical services.[27]

What is particularly appealing about examining the social determinants of health inequalities from the perspective of Rawls's theory is that the theory is egalitarian in orientation and yet justifies certain inequalities that might contribute to health inequalities. In addition, Norman Daniels's extension of Rawls links the protection of health to the protection of equality of opportunity, again setting up the potential for internal conflict. To see whether this combination of features leads to insight into the problem or simply to contradictions in the theory, we must examine the issue in more detail.

How does Rawls justify socioeconomic inequalities? Why would free and equal contractors not simply insist on strictly egalitarian distribution of all social goods, just as they insist on equal basic liberties and equal opportunity?

Rawls's answer is that it is irrational for contractors to insist on equality if doing so would make them worse off. Specifically, he argues that contractors would choose his Difference Principle, which permits inequalities provided that they work to make the worst-off groups in society as well off as possible.[28] The argument for the Difference Principle appears to suggest that relative inequality is less important than absolute well-being, a suggestion that is in tension with other aspects of Rawls's view. Thus he also insists that inequalities allowed by

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the Difference Principle should not undermine the value of political liberty and the requirements of fair equality of opportunity. The priority given these other principles over the Difference Principle thus limits the inference that Rawls has no concern about relative inequality. Specifically, as we shall see, these principles work together to constrain inequality and to preserve the social bases of self-respect for all.

Two points will help avoid misunderstanding of the Difference Principle and its justification. First, it is not a mere "trickle-down" principle but one that requires maximal flow in the direction of helping the worst-off groups. The worst off, and then the next worst off, and so on (Rawls calls this "chain connectedness"[29]) must be made as well off as possible, not merely just somewhat better off, as a trickle-down principle implies. The Difference Principle is thus much more demanding than a principle that would permit any degree of inequality provided there was some "trickle" of benefits to the worst off. Indeed, it is more egalitarian than alternative principles that merely assure the worse off a "decent" or "adequate" minimum. From what we have learned about the social determinants of health, the more demanding Difference Principle would also produce less health inequality than any proposed alternative principles that allow inequalities. By flattening the health gradient, it would also benefit middle-income groups, not simply the poorest. In this regard, its benefits are important beyond the level at which we have helped the worst off to achieve "sufficiency." This point provides a reply to those who suggest that the Difference Principle has no appeal once the worst off are sufficiently provided for.[30]

Second, when contractors evaluate how well off the principles they choose will make them, they judge their well-being by an index of "primary social goods."[31] The primary social goods, which Rawls thinks of as the "needs of citizens," include liberty, powers, opportunities, income and wealth, and the social bases of self-respect. (These objective measures of well-being should be contrasted with measures of happiness or desire-satisfaction that are familiar from utilitarian and welfare economic perspectives.) In his exposition of the Difference Principle, Rawls illustrates how it will work by asking us to con-

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sider only the simpler case of income inequalities. In doing so, he assumes that the level of income will correlate with the level of other social goods on the index.

This simplification should not mislead us, for, in crucial cases, the correlation may not obtain. For example, let us suppose that having "democratic" control over one's workplace is crucial to self-realization and the promotion of self-esteem.[32] Suppose further that hierarchical workplaces are more efficient than democratic ones, so that a system with hierarchical workplaces would have resources to redistribute that meant higher incomes for worst-off workers than democratic workplaces would permit. Then the Difference Principle does not clearly tell us whether the hierarchical workplace contains allowable inequalities since the worst off are better off in some ways but worse off in others. Without knowing the weighting of items in the index, we cannot use it to say clearly what inequalities are permitted. When we are evaluating which income inequalities are allowable, by asking which ones work to make the worst-off groups as well off as possible, we must, in any case, judge how well off groups are by reference to the whole index of primary goods—not simply the resulting income.

This point is of particular importance in the current discussion. Daniels's extension of Rawls treats health status as a determinant of the range of opportunity open to individuals. Since opportunity is included in the index, the effects of health inequalities are thereby included in the index.

Rawls says very little, however, about how items in the index are to be weighted. Therefore we have little guidance about how these primary goods are to be traded off against each other in its construction. This silence pertains not only to the use of the index in the contract situation, but also to its use, as we will examine more closely below, by a legislature trying to apply the principles of justice in a context in which many specific features of a society are known.

We can now say more directly why justice, as described by Rawls's principles, is good for our health. To understand this claim, let us start with the ideal case, a society governed by Rawls's principles of justice that seeks to achieve "democratic equality."[33] Consider what it requires with regard to the distri-

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bution of the social determinants of health. In such a society, all are guaranteed equal basic liberties, including the liberty of political participation. In addition, there are institutional safeguards aimed at assuring all, richer and poorer alike, the worth or value of political participation rights. Without such assurance, basic capabilities of citizens cannot develop. The recognition that all citizens must have these capabilities protected is critical to preserving self-esteem, in Rawls's view. Since there is evidence, as we have seen, that political participation is itself a social determinant of health, the Rawlsian ideal assures institutional protections that counter the usual effects of socioeconomic inequalities on participation and thus on health.

The Rawlsian ideal of democratic equality also involves conformity with a principle guaranteeing a fair distribution equality of opportunity. Not only are discriminatory barriers prohibited by the principle; it requires as well robust measures aimed at mitigating the effects of socioeconomic inequalities and other social contingencies on opportunity. In addition to equitable public education, such measures would include the provision of developmentally appropriate day care and early childhood interventions intended to promote the development of capabilities independently of the advantages of family background. Such measures match or go beyond the best models we see in European efforts at day care and early childhood education. We also note that the strategic importance of education for protecting equal opportunity has implications for all levels of education, including access to graduate and professional education.

The equal opportunity principle also requires extensive public-health, medical, and social-support services aimed at promoting normal functioning for all.[34] It even provides a rationale for the social costs of reasonable accommodation to incurable disabilities, as required by the Americans with Disabilities Act.[35] Because the principle aims at promoting normal functioning for *all* as a way of protecting opportunity for all, it simultaneously aims at both improving population health and reducing health inequalities. Obviously, this focus requires the provision of universal access to comprehensive health care, including public health, primary health care, and medical and social support services.

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To act justly in health policy, we must have knowledge about the causal pathways through which socioeconomic (and other) inequalities work to produce differential health outcomes. Suppose we learn, for example, that structural and organizational features of the workplace inducing stress and a sense of a loss of control tend to promote health inequalities. We should then view the modification of those features of workplace organization as a public-health requirement of the equal-opportunity principle in order to mitigate their negative effects on health. It would thus be placed on a par with the requirement that we reduce exposures to toxins in the workplace.[36]

Finally, in the ideal Rawlsian society, the Difference Principle places significant restrictions on allowable inequalities in income and wealth.[37] The inequalities allowed by this principle (in conjunction with the principles assuring equal opportunity and the value of political participation) are probably more constrained than those we observe in even the most industrialized societies. If so, then the inequalities that conform to the Difference Principle would produce a flatter gradient of health inequality than we currently observe in even the more extensive welfare systems of northern Europe.

In short, Rawls's principles of justice regulate the distribution of the key social determinants of health, including the social bases of self-respect. There is nothing about the theory, or Daniels's extension of it, that should make us focus narrowly on medical services. Properly understood, justice as fairness tells us what justice requires in the distribution of all socially controllable determinants of health.

We still face a theoretical issue of some interest. Even if the Rawlsian distribution of the determinants of health flattens health gradients further than what we observe in the most egalitarian, developed countries, we must still expect a residue of health inequalities. In part, this may happen because we may not have adequate knowledge of all the relevant causal pathways or interventions that are effective in modifying them. The theoretical issue is whether the theory requires us to reduce *further* those otherwise justifiable inequalities because of the inequalities in health status they create.

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We should not further reduce those socioeconomic inequalities if doing so reduces productivity to the extent that we can no longer support the institutional measures we already employ to promote health and reduce health inequalities. Our commitment to reducing health inequality should not require steps that threaten to make health worse for those with less-than-equal health status. So the theoretical issue reduces to this: would it ever be reasonable and rational for contractors to accept a tradeoff in which some health inequality is allowed in order to produce some nonhealth benefits for those with the worst health prospects?

We know that in real life people routinely trade health risks for other benefits. They do so when they commute longer distances for a better job or take a ski vacation. Some such trades raise questions of fairness. For example, when is hazard pay a benefit workers gain only because their opportunities are unfairly restricted, and when is it an appropriate exercise of their autonomy?[38] Many such trades we would not restrict, thinking it unjustifiably paternalistic to do so; others we see as unfair.

Rawlsian contractors, however, cannot make such trades on the basis of any specific knowledge of their own values. They cannot decide that their enjoyment of skiing makes it worth the risks to their knees or necks. To make the contract fair to all participants, and to achieve impartiality, Rawls imposes a thick "veil of ignorance" that blinds them to all knowledge about themselves, including their specific views of the good life. Instead, they must judge their well-being by reference to an index of primary social goods (noted earlier) that includes a weighted measure of rights, opportunities, powers, income and wealth, and the social bases of self-respect. When Kenneth Arrow first reviewed Rawls's theory, he argued that this index was inadequate because it failed to tell us how to compare the ill rich with the well poor.[39] Amartya Sen has argued that the index is insensitive to the way in which disease, disability, or other individual variations would create inequalities in the capabilities of people who had the same primary social goods.[40] By extending Rawls's theory to include health care through the equal opportunity account, some of Arrow's (and Sen's) criti-

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cism is undercut.[41] But even raising our question about residual health inequalities reminds us that the theory says too little about the construction of the index to provide us with a clear answer.

One of Rawls's central arguments for singling out a principle protecting equal basic liberties and giving it (lexical) priority over his other principles of justice is his claim that once people achieve some threshold level of material well-being, they would not trade away the fundamental importance of liberty for other goods.[42] Making such a trade might deny them the liberty to pursue their most cherished ideals, including their religious beliefs, whatever they turn out to be. Can we make the same argument about trading health for other goods?

There is some plausibility to the claim that rational people would refrain from trades of health for other goods. Loss of health may preclude us from pursuing what we most value in life. We do, after all, see people willing to trade almost anything to regain health once they lose it. If we take this argument seriously, we might conclude that Rawls should give opportunity—considered as including the effects of health status—a heavier weighting in the construction of the index than income alone.[43] Such a weighting would mean that absolute increases in income that might otherwise have justified increasing relative income inequality, according to the Difference Principle, now fail to justify that inequality because of the negative effects on opportunity. Although the income of the worst off would increase, they would not be better off according to the whole (weighted) index of primary social goods, and so the greater inequality would not be permitted. Rawls's simplifying assumption about income correlating with other goods fails in this case (as it did in the hypothetical example about workplace democracy cited earlier).

Nevertheless, there is also strong reason to think that the priority given to health, and thus opportunity, is not as clear-cut as the previous argument implies—especially where the trade is between a *risk* to health and other goods that people highly value. Refusing to allow any (*ex ante*) trades of health risks for other goods, even when the background conditions on choice are otherwise fair, may seem unjustifiably paternalistic,

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perhaps in a way that refusing to allow trades of basic liberties is not.

We propose a pragmatic route around this problem, one that has a precedent elsewhere in Rawls. Fairness in equality opportunity, Rawls admits, is only approximated even in an ideally just system, because we can only mitigate, not eliminate, the effects of family and other social contingencies.[44] For example, only if we were willing to violate widely respected parental liberties could we intrude into family life and "rescue" children from parental values that arguably interfere with equal opportunity. Similarly, though we give a general priority to equal opportunity over the Difference Principle, we cannot achieve complete equality in health any more than we can achieve completely equal opportunity. Even ideal theory does not produce perfect justice. Justice is always rough around the edges. Specifically, if we had good reason to think that "democratic equality" had flattened inequalities in accord with the principles of justice, then we might be inclined to think we had done as much as was reasonable to make health inequalities fair to all. The residual inequalities that emerge in conformance to the principles are not a "compromise" with what justice ideally requires; they are acceptable as just.

So far, we have been considering whether the theoretical question of a health tradeoff can be resolved from the perspective of individual contractors. Instead, suppose that the decision about such a tradeoff is to be made through the legislature in a society that conforms to Rawls's principles. Because those principles require effective political participation across all socioeconomic groups, we can suppose that groups most directly affected by any tradeoff decision have a voice in the decision. Since there is a residual health *gradient*, groups affected by the tradeoff include not only the worst off, but those in the middle as well. A democratic process that involved deliberation about the tradeoff and its effects might be the best we could do to provide a resolution of the unanswered theoretical question.[45]

In contrast, where the fair value of political participation is not adequately assured—and we doubt it is so assured in even our most democratic societies—we have much less confidence

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in the fairness of a democratic decision about how to trade health against other goods. It is much more likely under actual conditions that those who benefit most from the inequalities, i.e., those who are better off, also wield disproportionate political power and will influence decisions about tradeoffs to serve their interests. It may still be that the use of a democratic process in nonideal conditions is the fairest resolution we can practically achieve, but it still falls well short of what an ideally just democratic process involves.

We have focused on Rawlsian theory because it provides, however unintentionally, a developed account of how to distribute the social determinants of health. Other, competing theories of justice, including some recent proposals about "equal opportunity for welfare or advantage," offer no similarly developed framework for distributing the key social determinants of health.[46] On the other hand, Sen's account of the importance of an egalitarian distribution of "capabilities" actually resembles the account offered by Daniels (and others) of equal opportunity and normal functioning more than it seems at first.[47] Elizabeth Anderson has imaginatively focused the discussion of capabilities on those needed if citizens are to have "democratic equality."[48] The result is a striking convergence with Rawls's view of democratic equality—although Rawls's ability to talk about the fair distribution of social determinants of health follows directly from his principles, whereas Anderson must appeal intuitively to an account of the capabilities needed by citizens.

POLICY IMPLICATIONS FOR A JUST DISTRIBUTION OF THE SOCIAL DETERMINANTS OF HEALTH

We earlier suggested that the analyses of Whitehead and Dahlgren of health inequities (inequalities that are avoidable and unfair) are useful, provided that we can agree on what counts as avoidable and unfair. We then suggested that the Rawlsian account of justice as fairness provides a fuller account of what is fair and unfair in the distribution of the social determinants of health. The theory provides a more systematic way to think about which health inequalities are inequities.

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Compared to that ideal, most health inequalities that we now observe worldwide among socioeconomic and racial or ethnic groups are "inequities" that should be remedied. Even some countries with the shallowest health gradients, such as Sweden and England, have viewed their own health inequalities as unacceptable and have initiated policy measures to mitigate them. The broader efforts of the World Health Organization in this direction are, probably without exception, also aimed at true inequities.

A central policy implication of our discussion is that reform efforts to improve health inequalities must be intersectoral and not focused just on the traditional health sector. Health is produced not just by having access to medical prevention and treatment, but, to a measurably greater extent, by the cumulative experience of social conditions across the life course. In other words, by the time a sixty-year-old patient is brought to the emergency room to receive medical treatment for a heart attack, that encounter represents the result of bodily insults accumulated over a lifetime. Medical care is, figuratively speaking, "the ambulance waiting at the bottom of the cliff." Much of the contemporary discussion about increasing access to medical care as a means of reducing health inequalities misses this point. An emphasis on intersectoral reform will recognize the primacy of social conditions, such as access to basic education, levels of material deprivation, a healthy workplace environment, and equality of political participation in determining the health achievement of societies.[49]

Before saying more about intersectoral reform, we want to head off what from our view is a mistaken inference—namely that we should ignore medical services and health-sector reform because other steps have a bigger payoff. Even if we had a highly just distribution of the social determinants of health and of public-health measures, people would still become ill and need medical services. The fair design of a health system should give weight to meeting actual medical needs.

We might think of those with known needs and those who are ill as "identified victims," whereas we might think of those whose lives would be spared illness by robust public-health measures and a fair distribution of social determinants as "statis-

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tical victims." Several theoretical perspectives, both utilitarian and nonutilitarian, would hold that we should consider all these lives impartially, judging statistical lives saved to be just as valuable or important as identified victims. Utilitarian approaches would push us to maximize net benefit by allocating resources from saving identified lives to saving statistical ones.

Other reasonable considerations, however, temper our inclination to reallocate in such an impartial way from identified to statistical victims. Many of us give some extra moral weight to the urgent needs of those already ill. Others, through their roles as medical providers, may legitimately believe that the good that they can achieve through their control over the delivery of medical care has a greater claim on them than the good that would be brought about by more indirect measures beyond their control. More generally, many of us will be connected as family members and friends to the identified victims and will feel that we have "agent-relative" obligations to assist them that supersede the obligations we have to more distant, statistical victims.

It is impossible to dismiss the relevance of these other considerations. Consequently, we do not draw the inference that impartiality or rationality considerations might seem to support: namely, that we should immediately reallocate resources away from medical services to public-health measures or a fairer distribution of social determinants in accordance with some algorithm based on the relative benefit, neutrally calculated, between statistical and identified lives. This is not to imply, however, that no reallocations are justifiable. No doubt some are, in light of what we have argued.[50]

What sorts of social policies should governments pursue in order to reduce health inequalities? Certainly, the menu of options should include equalizing access to medical care; but it should also include a broader set of policies aimed at equalizing individual life opportunities, such as investment in basic education, affordable housing, income security, and other forms of antipoverty policy. Though the connection between these broad social policies and health may seem somewhat remote, and though such policies are rarely linked to issues of health in our public-policy discussions, growing evidence suggests that they

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should be so linked. The kinds of policies suggested by a social-determinants perspective encompass a much broader range of instruments than would be ordinarily considered for improving the health of the population. We discuss three such examples of social policies that hold promise of abating socioeconomic disparities in health: investment in early childhood development, improvement in the quality of the work environment, and reduction in income inequality.

The Case for Early Life Intervention

Growing evidence points to the importance of the early childhood environment in influencing the behavior, learning, and health of individuals later in the life course. Providing equal opportunities within a Rawlsian framework translates into intervening as early in life as possible. Several studies have demonstrated the benefits of early supportive environments for children. In the Perry High/Scope Project, children in poor economic circumstances were provided a high-quality early childhood development program between the ages of three and five.[51] Compared to the control group, those in the intervention group completed more schooling by age twenty-seven, were more likely to be employed, own a home, and be married with children, experienced fewer criminal problems and teenage pregnancies, and were far less likely to have mental-health problems.

Compensatory education and nutrition in the early years of life (as exemplified by the Head Start and WIC programs) have been similarly shown to yield important gains for the most disadvantaged groups. As part of Lyndon Johnson's War on Poverty, the U.S. government introduced two small compensatory-education programs—Head Start for preschoolers, and Chapter 1 (now Title 1) for elementary school children. Evaluations of these programs indicate that children who enroll in them learn more than those who do not. In turn, educational achievement is a powerful predictor of health in later life, partly because education provides access to employment and income, and partly because education has a direct influence on health behavior in adulthood, including diet, smoking, and physical activity.[52]

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A similarly persuasive case can be made for nutritional supplementation in low-income women and children. An analysis of the National Maternal and Infant Health Survey found that participation of low-income pregnant women in the WIC program (the Special Supplemental Nutrition Program for Women, Infants, and Children) was associated with about a 40 percent reduction in the risk of subsequent infant death.[53] A mother's nutritional state affects her infant's chance of death not just in the first year of life but also throughout the life course. Thus, a woman's pre-pregnant weight is one of the strongest predictors of her child's birth weight, and, in turn, low birth weight has been linked with increased risks of coronary heart disease, hypertension, and diabetes in later life. It follows that investing in policies to reduce early adverse influences may produce benefits not only in the present, but also in the long run and for future generations.

The Case for Improving the Quality of the Work Environment

We alluded earlier to the finding that the health status of workers is closely linked to the quality of their work environment, specifically to the amount of control and autonomy available to workers on their jobs. Low-control work environments—such as monotonous, machine-paced work (e.g., factory assembly lines) or jobs involving little opportunity for learning and utilization of new skills (e.g., supermarket cashiers)—tend to be concentrated among low-income occupations. The work of Marmot and his colleagues has shown that social disparities in health arise partly as a consequence of the way labor markets sort individuals into positions of unequal authority and control.[54] Exposure to low-control, high-demand job conditions not only is more common in lower-status occupations, but also places workers at increased risk of hypertension, cardiovascular disease, mental illness, musculoskeletal disease, sickness absence, and physical disability.[55]

A growing number of international case studies has concluded that it is possible to improve the level of control in workplaces by several means: increasing the variety of different tasks in the production process; encouraging workforce participation in the production process; and allowing more

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flexible work arrangements, such as altering the patterns of shift work, to make them less disruptive of workers' lives.[56] In some cases it may even be possible to redesign the workplace and enhance worker autonomy without affecting productivity, since sickness absence may diminish as a consequence of a healthier workplace.

The Case for Income Redistribution

Many of the measures suggested by the social-determinants perspective tend to fall into the category of antipoverty policy. However, research on the social determinants of health warns us that antipoverty policies *do not go far enough* in reducing unjust health disparities. Though none would disagree about putting priority on reducing the plight of the worst off, the fact is that health inequalities occur as a gradient: the poor have worse health than the near-poor, the near-poor fare worse than the lower middle class, the lower middle class do worse than the upper middle class, and so on up the economic ladder. Addressing the social gradient in health requires action above and beyond the elimination of poverty.

To address comprehensively the problem of health inequalities, governments must begin to address the issue of economic inequalities *per se*. As we noted above, growing international and intranational evidence suggests that the extent of socioeconomic disparities—that is, the size of the gap in incomes and assets between the top and bottom of society—is itself an important determinant of the health achievement of society, independent of the average standard of living.[57] Most importantly, economic disparities seem to influence the degree of equality in political participation (in the form of voting, donating to campaigns, contacting elected officials, and other forms of political activity): the more unequal the distribution of incomes and assets, the more skewed the patterns of political participation, and, consequently, the greater the degree of political exclusion of disadvantaged groups.[58]

Inequalities in political participation in turn determine the kinds of policies passed by national and local governments. For example, Kim Hill and his colleagues carried out a pooled time-series analysis for the fifty U.S. states from 1978 to 1990 to

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examine the relationship between the degree of mobilization of lower-class voters at election time and the generosity of welfare benefits provided by state governments.[59] Even after adjusting for other factors that might predict state welfare policies—such as the degree of public liberalism in the state, the federal government's welfare cost-matching rate for individual states, the state unemployment rate and median income, and the state tax effort—robust relationships were found between the extent of political participation by lower-class voters and the degree of generosity of state welfare payments. In other words, *who participates* matters for political outcomes, and the resulting policies have an important impact on the opportunities for the poor to lead a healthy life.

For both of the foregoing reasons—that it yields a higher level of health achievement as well as greater political participation—the reduction of income disparity ought to be a priority of governments concerned about addressing social inequalities in health. Although the scope of this essay precludes further consideration here, a number of levers do exist by which governments could address the problem of income inequality, spanning from the radical (a commitment to sustained full employment, collective wage bargaining, and progressive taxation) to the incremental (expansion of the earned income tax credit, increased child care credit, and a raise in the minimum wage).[60]

Implications for International Development Theory

Our discussion has implications for international development theory, as well as for the economic choices confronted by industrialized countries. To the extent that income distribution matters for the health status of given populations, it is not obvious that giving strict priority to economic growth is the optimal strategy for maximizing social welfare. Raising everyone's income will improve the health status of the poor (the trickle-down approach), but not as much as paying attention to the *distribution* of the social product. Within the developing world, a comparison of the province of Kerala in India with more unequal countries like Brazil and South Africa illustrates this point. Despite having only a third to a quarter of the income of Brazil or South Africa (and thereby having a higher

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prevalence of poverty in the absolute sense), the citizens of Kerala nonetheless live longer, most likely as a result of the higher priority that the government of Kerala accords to a fair distribution of economic gains.[61]

The real issue for developing countries is what *kind* of economic growth is salutary. Hence, Drèze and Sen distinguish between two types of successes in the rapid reduction of mortality, which they term "growth-mediated" and "support-led" processes.[62] The former works mainly *through* fast economic growth, exemplified by mortality reductions in places like South Korea and Hong Kong. Their successes depended on the growth process being wide-based and participatory (for example, applying full employment policies) and on the gains from economic growth being utilized to expand relevant social services in the public sector, particularly in health care and education. The experiences of these states stand in stark contrast to the example of countries like Brazil, which have similarly achieved rapid economic growth but lagged behind in health improvements.

In contrast to growth-mediated processes, "support-led" processes operate not through fast economic growth but through governments giving high priority to the provision of social services that reduce mortality and enhance the quality of life. Examples include China, Costa Rica, and the Indian state of Kerala (mentioned above).

A similar choice, between policies emphasizing growth versus those promoting greater equality, applies to developed nations as well. Application of the Rawlsian Difference Principle suggests that a society like the United States has much room to move toward a more equitable (perhaps a more European) distribution of its national income without suffering a loss in productivity or growth. At the same time it would benefit from a gain in the health status of its citizens.

SOME CONCLUDING REMARKS ABOUT BIOETHICS

We noted earlier that bioethics has generally tended to focus on medicine at the point of delivery, attending inadequately to determinants of health "upstream" from the medical system

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itself. We have tried to remedy that by putting together two elements: empirical findings about the social determinants of health, and the result of a philosophical attempt to construct a theory of justice that might apply to any society. We arrive at the result that social justice, as defined by that theory, is good for our health. In a society that complies with its principles of justice, health inequalities will be minimized and population health status will be improved. A theory of social justice turns out to be a theory about how to distribute health status in a just way, at least if the social science is correct.

The failure of bioethics to look at the social determinants of population health is not primarily a philosophical failing, nor is it simply disciplinary blindness to the social-science or public-health literature. People in bioethics, like the public more generally, concentrate on medical care rather than social determinants, for complex sociological, political, and ideological reasons that we can only mention here. The public, encouraged by scientists and the media, is fascinated by every new biomedical discovery and has come to believe that most of our "success" in improving population health is the result of exotic science. Vast economic interests benefit from this orientation of public and bioethical attention. Economic incentives for people in bioethics come largely from medicine and the scientific and policy institutions that interact with medical delivery. The idea that scientific medicine is responsible for our health blinds us to socioeconomic inequality as a source of inequity in the realization of opportunity for health across the population. Science, we are told, can rescue us all from our shared biological fate, and so we should all unite in supporting a focus on medicine and, if we care about justice, on the equitable access of all to its benefits. Challenging deeper inequalities in society, however, is divisive, not unifying; it threatens those with the greatest power and the most to lose. In the absence of well-organized social movements capable of challenging that inequality, the complaints of public-health advocates pointing the need for more basic change, rather than simply joining existing forces asking for more and better medical care, can seem utopian.

There may be more here than an extension of the scope of Rawlsian moral theory. Earlier, we suggested that challenging

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Rawls's construct to address questions about the fair distribution of the social determinants of health might show the theory to be generalizable in fruitful ways. This generalizability is analogous to the increase in scope and power of a nonmoral theory when we discover that it can explain phenomena beyond the domain for which its laws were initially developed. What exactly is the analogy?

When an empirical theory turns out to explain new phenomena that were not part of the evidentiary base for its laws, we tend to conclude that the concepts incorporated in it are "projectible" in a desired way. We may think of them as better confirmed as a way of dividing up or describing the world. Rawls begins with certain political concepts thought crucial to our well-being—to meeting our needs as free and equal citizens of a democracy. Using these ideas, the goal was to identify terms of cooperation that all free and equal citizens could agree are fair and reasonable. It then turns out, given the social-science literature, that the aspects of well-being captured by these ideas expand to include the health of the population as well. Whatever controversy might have been thought to surround some of these political components of well-being, they do connect—albeit empirically—to some incontrovertibly objective components of our social well-being, namely, the health of the population. If this were an empirical rather than a normative theory, we would think the evidence of projectibility counted in its favor, constituting support for the theory. Is there additional "support" for Rawls's theory?

It turns out that the support we now give the theory might not be greatly reduced even if the facts were different about the relationship between socioeconomic inequality and health. However, that does not mean we should not add to the support we think the theory has if it turns out to have the projectibility described earlier. A lack of evidence of greater projectibility is not evidence against a theory; it is and should be a neutral finding. If, however, we found that population health was undermined by greater political well-being of the sort the original theory talked about (before its extension), then we would have a puzzle to address: why is one aspect of our well-being working in opposition to other elements of it?

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This discussion is admittedly too brief to establish a firm conclusion, but we are inclined to think there is some corroborative support for Rawls's theory in the fact that it generalizes to the phenomena of population health in this way. It is the coherence among these different areas of evidence and principle that gives us grounds for thinking the theory has additional justification.[63] This does not mean, of course, that standing objections to the theory, which we have deliberately not addressed, should be ignored.

Another lesson is illustrated by our results. Ethical inquiry is not just one kind of inquiry involving one type of method. This is true for inquiry into practical ethical issues, including bioethics. Sometimes the inquiry requires the importation of tools from political philosophy, from ethical theory, and from the social sciences (as we have done). Sometimes, depending on the problem, we make better progress by examining specific cases carefully and then trying to move to the level of principles and theory. Sometimes we are better off deploying theory or theory-based considerations and refining and adapting them in light of what we learn about particular cases and social science (as we have also done). Since ethical inquiry answers many different kinds of questions, this variability in appropriate method should not surprise us.

Since it is the overall coherence of our system of beliefs that provides us with justification for specific parts of it, we should not become enamored of the tools developed for or appropriate to specific aspects of ethical inquiry and overgeneralize about their importance to all inquiry. In some areas of inquiry in bioethics (or ethics more generally), progress is doomed if we remain insensitive to the local texture of a problem, including the way in which a particular society's beliefs play a role in its policies. But this observation should not lead us to question the relevance of reasons, principles, or theory that purports to bear on issues more universally, despite local texture. We risk impoverishing our inquiry if we insist on limiting ourselves to tools that are best designed for certain specific tasks when our project involves integrating those tasks with others.[64]

No doubt an examination of what policy regarding the distribution of health in a particular population is fair or just will

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have to take into account some aspects of local beliefs and culture. The same inquiry into policy must also attend to the general implications of social science and political philosophy where they frame the problems raised by local policy.

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ENDNOTES

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[27]Daniels, *Just Health Care*. John Rawls, *Political Liberalism* (New York: Columbia University Press, 1993).

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[29]Rawls, *A Theory of Justice*.

[30]Amy Gutmann and Dennis Thompson, *Democratic Disagreement* (Cambridge, Mass: Harvard University Press, 1995).

[31]Rawls, *A Theory of Justice*, 62; *Political Liberalism*, chap. 5.

[32]This example is taken from Joshua Cohen, "The Pareto Argument," unpublished manuscript.

[33]Daniels, "Rawls's Egalitarianism."

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[34]Daniels, *Just Health Care*. Norman Daniels, Donald W. Light, and Ronald L. Caplan, *Benchmarks of Fairness for Health Care Reform* (New York: Oxford University Press, 1996), 41–44.

[35]Norman Daniels, "Mental Disabilities, Equal Opportunity, and the ADA," in Richard J. Bonnie and John Monahan, eds., *Mental Disorder, Work Disability, and the Law* (Chicago: University of Chicago Press, 1996), 282–297.

[36]Daniels, *Just Health Care,* chaps. 7–8.

[37]Cohen ("Incentives, Inequality, and Community") has argued that a *strict* interpretation of the Difference Principle would allow few incentive-based inequalities; for a more permissive view, see Daniels, "Rawls's Egalitarianism."

[38]Daniels, *Just Health Care,* chap. 7.

[39]Kenneth Arrow, "Uncertainty and the Welfare Economics of Medical Care," *American Economic Review* 53 (1963): 941–973.

[40]Amartya K. Sen, "Equality of What?" in Sterling M. McMurrin, ed., *Tanner Lectures on Human Values*, vol. 1 (Cambridge: Cambridge University Press, 1980). Amartya K. Sen, *Inequality Reexamined* (Cambridge, Mass.: Harvard University Press, 1992).

[41]Norman Daniels, "Equality of What: Welfare, Resources, or Capabilities?" *Philosophy and Phenomenological Research* 50 (1990): 273–296.

[42]Rawls, *A Theory of Justice,* 243–251.

[43]Rawls does suggest, since fair equality of opportunity is given priority over the Difference Principle, that within the index, we can assume opportunity has a heavier weighting. Rawls, *A Theory of Justice*, 93.

[44]James Fishkin, *Justice, Equal Opportunity, and the Family* (New Haven, Conn.: Yale University Press, 1983).

[45]Norman Daniels and James E. Sabin, "Limits to Health Care: Fair Procedures, Democratic Deliberation, and the Legitimacy Problem for Insurers," *Philosophy and Public Affairs* 26 (1997): 303–350.

[46]Richard J. Arneson, "Equality and Equal Opportunity for Welfare," *Philosophical Studies* 54 (1988): 79–95. Gerald A. Cohen, "On the Currency of Egalitarian Justice," *Ethics* 99 (1989): 906–944. Roemer, *Equality of Opportunity*, chap. 12–13.

[47]For Sen's account, see Sen, *Inequality Reexamined*, chaps. 1–5, 9. For the account offered by Daniels and others, see Daniels, "Equality of What: Welfare, Resources, or Capabilities?"; A. Buchanan et al., *From Chance to Choice: Genetics and the Just Society* (New York: Cambridge University Press, in press).

[48]Elizabeth Anderson, "What is the Point of Equality?" *Ethics* 109 (2) (January 1999): 287–337; cf. Daniels, "Rawls's Egalitarianism."

[49]John N. Lavis and Gregory L. Stoddart, "Can We Have Too Much Health Care?" *Dædalus* 123 (4) (1994): 43–60.

[50]Ibid.

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[53]Nancy E. Moss and Karen Carver, "The Effect of WIC and Medicaid on Infant Mortality in the United States," *American Journal of Public Health* 88 (1998): 1354–1361.

[54]Michael G. Marmot et al., "Contribution of Job Control and Other Risk Factors to Social Variations in Coronary Heart Disease Incidence," *Lancet* 350 (1997): 235–239.

[55]Robert A. Karasek and Töres Theorell, *Health Work* (New York: Basic Books, 1990), 83–157.

[56]Acheson et al., *Report of the Independent Inquiry into Inequalities in Health,* 48–50.

[57]Kawachi et al., *Income Inequality and Health.*

[58]Kawachi and Kennedy, "Health and Social Cohesion"; "Income Inequality and Health."

[59]Kim Quaile Hill, Jan E. Leighley, and Angela Hinton-Andersson, "Lower-class Mobilization and Policy Linkage in the U.S. States," *American Journal of Political Science* 39 (1995): 75–86.

[60]Kawachi et al., *Income Inequality and Health,* xxviii-xxx.

[61]Amartya K. Sen, "Mortality as an Indicator of Economic Success and Failure," *The Economic Journal* 108 (1998): 1–25.

[62]Jean Drèze and Amartya Sen, *Hunger and Public Action* (Oxford: Clarendon Press, 1989), 183–187.

[63]Norman Daniels, "Wide Reflective Equilibrium and Theory Acceptance in Ethics," *Journal of Philosophy* 76 (1979): 256–282.

[64]Daniels, *Justice and Justification,* 333–352.

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Very few people own battle tanks for personal enjoyment. Such vehicles are not offered as prizes in lotteries or advertising programs or featured in the *Lifestyles of the Rich and Famous*. New homes, BMWs, tropical vacations, yes, but not tanks. And yet, under some circumstances, one might die if not for one then at least for lack of one.

The parallel with heart-lung transplants should be apparent. The services of the health-care system, like those of the military, are not wanted for their own sake. When they are called on, they are *needed*, and the need may be a matter of life or death. While in both cases having the services when they are needed is much better than not having them, it is far better still not to need them at all. The most sophisticated and effective health care in the world cannot produce results as good as simply remaining healthy in the first place. This is obvious to anyone who has ever been a patient—or been in battle—and our common understanding is pretty clear on the value of both health and peace.

Robert G. Evans

From "Health Care as a Threat to Health: Defense, Opulence, and the Social Environment"
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Larry R. Churchill

Are We Professionals? A Critical Look at the Social Role of Bioethicists

BIOETHICS CAN BE DEFINED as the branch of ethics that investigates problems arising from medicine and biological innovation.[1] Over the past decade it has had remarkable growth and experienced increasing social legitimacy. A national bioethics commission was set to work in 1995 and so far has issued reports on cloning and human-subjects research. The National Human Genome Research Institute has set aside 5 percent of its annual research budget since 1990 for investigations into the social and ethical implications of mapping the human genome through its Ethical, Legal, and Social Implications Program. The National Institutes of Health have established a Department of Clinical Bioethics, and the American Medical Association has created a new Institute for Ethics. Funding opportunities for bioethics research are more numerous than ever, and an interest in "empirical bioethics" has attracted scholars from medicine and the social sciences who previously were not engaged in this effort. Bioethics is enjoying an exceptional period of growth and prominence.

My aim in this essay is to raise questions about the mission and purpose of bioethics. Its continuing transformation from an inquiry on the disciplinary margins to an accepted social and institutional presence makes this questioning timely. What is the appropriate social role of bioethics as a field of study? What are the responsibilities of bioethicists as practitioners in this

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field? Who benefits from the work? Is bioethics in any sense a profession?

This may seem like an odd set of questions to raise. Why should anyone suppose that bioethics has a purpose different from any other academic field of study? We do not routinely ask about the social purposes of philosophers, historians, or anthropologists. We assume that the discovery and transmission of knowledge pertinent to these areas is a sufficient purpose and whatever larger social or public good that accrues from work in these fields is a general good and probably best left unspecified. Trying to claim more direct social benefit from such work may be chauvinistic and even risky, raising questions about how to measure its utility and thereby potentially jeopardizing academic freedom. Why single out bioethics for this sort of inquiry?

Bioethics is different for two reasons. First, bioethics is unusual precisely because of its increasing acceptance in medical and health-care institutions, as well as its social prominence and media appeal. Ethics committees are a routine part of the infrastructure of modern hospitals and are called upon for ethical analyses of biomedical innovations and controversial cases. Bioethicists also increasingly perform in the public eye, testifying before congressional and state legislative committees and playing prominent roles in educational programs for both professionals and the public. With this increasing public presence comes increased responsibility for using well these fora and platforms and their implicit authority. Second, it should be remembered that bioethics has come into prominence over the past thirty years—and especially over the last ten—not because of the discovery of a powerful new set of methods or tools. Rather, the rise of bioethics is the result of a widely felt need to address social and ethical problems emerging from innovations in the life sciences and medical care. Bioethics was spawned by practical problems, not methodological or theoretical ones. So it seems appropriate to ask how well bioethicists have done in responding to these problems, and who has benefited from our work.

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DANGEROUS OR RIDICULOUS (OR BOTH)?

David Hume said, "the errors in religion are dangerous; those in philosophy only ridiculous."[2] Hume, of course, wrote in a time in which religious wars were a fresh memory in his native Scotland. Moreover, one of Hume's aims was to make the study of ethics more empirical and less speculative, and his disdain for abstract philosophical theorizing is a thread woven through many of his writings. It would be tempting simply to echo Hume's assessment as it applies to philosophical errors in bioethics. Bioethical disputes—as measured by the debates in journals and conferences in the United States—often seem to be remote from the values of ordinary people and largely irrelevant to the decisions they encounter in health care. In this sense, philosophical theorizing might be considered harmless entertainment, which if taken too seriously would look ridiculous, as several Monty Python skits have skillfully demonstrated.

Take for example the recent metaethical dispute about whether the justification for practical ethical choices can be *deduced* from general principles of ethics, or whether the connection between principles and specific actions is best described as one of "coherence."[3] This debate is, I strongly suspect, remote and largely irrelevant to the vast majority of ordinary citizens trying to make health-care decisions for themselves and their families. Nonphilosophers do not expect or need this level of consistency to be assured that their actions have moral integrity, so our concern with it might qualify as a form of silliness. Yet philosophical errors in bioethics may be more than ridiculous; they may also be dangerous. Modes of reasoning that are taken with utmost seriousness in a bioethics journal may be humorous in a Monty Python skit, but hazardous in a clinical setting.

The hazard can be readily illustrated by the sorts of misfires that occur when the moral experiences of patients do not match bioethical categories. For example, a patient who interprets his illness from within a religious matrix of "sin, suffering, forgiveness, and healing" may find a total mismatch between his ethical scheme and those of both physicians and bioethicists.

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One of my earliest clinical experiences as a bioethics "consultant" involved just such a situation.[4] A middle-aged female patient was being seen by a surgeon concerning the reappearance of a malignancy. The patient had undergone a below-the-knee amputation of her left leg in the first effort to cure her. Although the surgeon remained optimistic about the possibilities for a good outcome from a second surgery, the patient was adamant in her refusal. I was asked to join the discussion.

As a new ethicist on the scene, I approached my task armed with a sophisticated variety of moral concepts and maneuvers. I was well prepared, or so I thought, to discuss various interpretations of patient autonomy, legal rights of refusal, shades of decisional competence, and the like. But the patient spoke a different language, and her narrative of refusal was laced with terms like "sacrifice," "atonement," "doing the Lord's work," and "being a healing witness." My role was less one of ethics consultant and more one of religious translator and cultural interpreter. But the temptation to assume that the patient was not speaking a different language, but rather speaking my language of "ethics" in a sloppy way, was powerful. I have occasionally encountered this temptation in medical students as well, as they try to make sense of patient "preferences." One student reported, "Mr. McCormick says that he doesn't think the treatment we are providing is helping him, but he wants us to continue anyway. This is a contradiction; it makes no sense." Of course, knowing whether or how it makes sense depends on a better understanding of Mr. McCormick. It may make not logical sense but human sense, expressing a consistency grounded in Mr. McCormick's values or simply his need and hope not to be turned out of the hospital or abandoned. The "contradiction" may, of course, be real, in which case logical persuasion may be useful, but more likely "contradiction" is an inappropriate judgment and appears only when formal logic is imposed over lived logic, when the aspiring physician's story about McCormick is substituted for McCormick's story about himself, his moral autobiography.

Another kind of hazard for patients and their families comes from bioethics consultants and bioethics committees who are part of institutional and professional power structures and

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serve these institutions and their needs rather than the needs of patients and families whose lives and health are the focus of discussion. I have written previously about this sort of peril.[5] It arises in part because it is mainly institutions and their staff professionals—rather than patients and their families—that pose and frame most of the issues for bioethicists and ethics committees. It is only natural to want to respond helpfully to those with whom one works routinely, who are in positions of evaluation and remuneration. It is the natural character of this desire to be helpful that blunts the recognition of being captured by institutional agendas.

CORE COMPETENCIES, ELITISM, AND THE VARIETIES OF MORAL EXPERIENCE

A partial answer to questions about the role and purpose of bioethics has been issued in the recent report of the American Society for Bioethics and Humanities (ASBH) entitled *Core Competencies for Health Care Ethics Consultation*.[6] Consultation is not, of course, all of bioethics, but for many in the field it is a significant component of their work. Even for those who think of bioethics as a scholarly and teaching field, rather than a consulting field, what bioethics consultants say about themselves and their work is important. Whatever paradigm of bioethics consulting is embraced inevitably influences notions of scholarship and teaching, including what problems are studied and what pedagogical methods are used.

The goal of bioethics consultation, the *Core Competencies* report says, is "to improve the provision of health care and its outcome through the identification, analysis, and resolution of ethical issues as they emerge in clinical cases."[7] This puts bioethics work into full synchrony with that of doctors, nurses, chaplains, and social workers. As members of the health-care team, bioethicists' special tasks include clarifying the related normative issues, identifying a range of morally acceptable options, and facilitating the building of consensus. The report goes on to say that ethics consultants accomplish this through the exercise of three categories of skills: ethical assessment skills, process skills, and interpersonal skills, which are further

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divided into "basic" and "advanced," the latter being required for "more complex cases."[8] In general, the report is carefully done and portions of it are genuinely useful, especially the list of skills that anyone engaged in this work might find valuable. No doubt this document would have been helpful to me when I was first called to join in clinical conversations, including the instance recounted above.

The report states clearly and emphatically that the listing of core competencies does not constitute an effort at professional standardization, such as the certification of consultants or the accreditation of training programs for them. The report calls its recommendations "voluntary guidelines" and lists numerous problems with certification: the adoption of an authoritarian consulting style that tends to give answers rather than facilitate consensus; the displacement of health professionals from their appropriate roles; the undermining of the disciplinary diversity necessary to bring all the requisite skills to the task; and the inability to frame anything like a certifying exam for ethics consultation. Certification in ethics consultation, the report concludes, is "premature at best."[9] These are all, indeed, good reasons to abstain from certification and accreditation, and perhaps those who find the movement toward establishing professional standards in bioethics work worrisome should be reassured.

But I am not reassured. I find that this report—including the disclaimers and the lists of reasons to avoid certification *at this time*—only accentuates my worries. The tone of the report, its history, and several of its features belie the disclaimers. First, if the authors had intended this report as a discussion piece, or a tentative working statement of one way to go about bioethics consulting, I doubt they would have stated—as they do in the introduction—that these "core competencies" are "necessary for doing bioethics consultation."[10] I think the authors intended this report to be seen as authoritative, and the history of the report lends credibility to this interpretation, since it is the culmination of a joint task force on "Standards for Bioethics Consultation," formed by two of the three organizations that merged to form the ASBH.[11] The fact that "standards" are now called "core competencies" does little to make them appear less

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authoritative. Similarly, the report makes a self-assessment of its authority in creating "voluntary guidelines," especially when the voluntariness is linked to statements about the "current state of knowledge" in an "evolving" field.[12] All this has the tone of aspirations for more rigorous standardization in the future.

But let me take the report on its own terms and assume that "core competencies" are intended neither to set professional standards nor to lead in that direction. Still, the problems are substantial. The effort to articulate anything like core competencies deflects attention from the questions I posed earlier: What is the social purpose of bioethics? Who benefits from it? It deflects attention from asking these questions precisely because it focuses narrowly on a list of competencies and those who possess them. This sets the stage for internal debates about who is qualified to do what and tends to dampen the ability or willingness of those who are "competent"—or striving to become so—to ask broader and deeper self-critical questions. So it turns attention inward onto a small group of specialists, instead of outward onto the larger role of bioethics. More important, concern with professional competencies tends to make bioethics an elitist enterprise, the special province of those with the proper training and skills. As Nancy King has correctly noted, the report stresses the complementary nature of diverse competencies from fields such as philosophy, medicine, social work, and the like, but completely neglects and thereby marginalizes the role of the community or nonprofessional members of ethics committees and their role in ethics consultations.[13] This neglect and marginalization is antithetical to ethics as a human enterprise.

Ethics, understood as the capacity to think critically about moral values and direct our actions in terms of such values, is a generic human capacity. Except for sociopaths, it is common to all of us, and skill in ethics does not lend itself easily to encapsulation in theoretical categories, core competencies, or a professional specialty. William James, in *The Varieties of Religious Experience* (the Gifford Lectures, 1901–1902), said: "As there appears to be no one elementary religious emotion, but only a common storehouse of emotions upon which religious

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objects may draw, so there might conceivably prove to be no one specific and essential kind of religious object, and no one specific and essential kind of religious act."[14]

What James said about religious experience is equally true of moral experience. It is not one kind of thing, but a complex involving many cognitive and emotional activities. In terms of its conceptual components, it is part logical analysis, part leaps of imagination, part storytelling and narrative threading, part reflecting, remembering, and deliberating. Likewise, moral experience can involve a very wide range of human emotions, and it is impossible to tell—in advance or in general terms—just what critical faculties of mind or range of emotions will or should be engaged for any given individual at any point in time. This means, among other things, that no ethical competencies are ultimately "core," and standard processes for ethics consulting will be of limited use. What counts as competency for successfully negotiating one morally troubling situation may not for another situation. What matters far more are insight and agility in moving among a variety of competencies to select the appropriate ones for the problem at hand. Again to quote William James: "A large acquaintance with particulars often makes us wiser than the possession of abstract formulas."[15]

Evoking the work of William James may be helpful for reasons of subject matter as well as methodology, especially if it draws attention to religious experiences and traditions as sources of moral insight. Many bioethicists know a great deal about Kant and Mill, Rawls and Nozick, and Beauchamp and Childress. Far fewer know how to navigate their way through Judaism, Christianity, and Islam, and the numerous variations within each of these traditions. Yet if we were to ask about the sources of moral insight on which they relied, most patients and their families would point to a religious tradition rather than a philosophical one. This means that the mismatch of competencies I experienced in one of my first clinical encounters, recounted above, is likely a routine occurrence.

Many bioethicists will appreciate my point and respond that they have learned a good deal about the belief systems of the major Western religions, especially those beliefs that relate to health-care decisions at the beginning and end of life. The

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beliefs of Jehovah's Witnesses, which prohibit the transfusion of blood and the use of most blood products, are a good example here, for they create a situation in which medical and social norms run directly counter to religious convictions, and awareness of this is an important component in rendering care that is not only medically sound but morally appropriate. Yet this example is also misleading, for it presumes that the way religion shapes and informs values for health-care decisions is usually explicit and discernible in terms of specific beliefs. The moral wisdom available to religious persons often does not germinate from formal theological principles, or issue in convictions about specific medical interventions. Religious systems, unlike philosophical systems, are primarily efforts not to "get it right" in one's head, but to "get it right" in one's life. Religion is less a system of belief than a set of rituals and practices that bespeak a way of life. This is especially true for the noncreedal religions, such as Judaism, that are built around interpretive communities of faith and practice rather than formal doctrines. But even in creedal religions like Protestant Christianity, it is rituals and practices, as much as theological doctrine, that give coherence to religious ethics. This means that the information bioethicists need in order to understand the moral reasoning of religious persons is generally not available in books, but only acquired through reflective engagement with people in their communities of faith. Here a piece of Wittgensteinian advice is apt: "Don't think, but look!"[16]

Bioethics consultants, especially those who contributed to the *Core Competencies* report, might well respond that engagement with real people rather than academics—looking instead of thinking—is precisely what consultation is and what the report endorses. This misses the point. The problem is not that patients and their families are not engaged, but that the report encourages a mode of engagement that is presumptive and pretentious about who is "competent" in ethical deliberation and who is not.

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WHO WANTS OUR ADVICE? WOULD WE WANT OUR OWN ADVICE?

One test of whether bioethicists are "competent"—and whether bioethics consulting is helpful or hazardous—is whether people facing difficult health-care decisions seek our services. Health professionals, hospitals, national commissions, research review boards, and a variety of other organizations and groups do, of course, seek our services, but what about ordinary citizens? During the course of a typical day tens of thousands of people make major decisions about the end of life, about organ transplantation, about participation in clinical research, and a wide variety of other important health-care choices without ever consulting a bioethicist. At noted earlier, ethics committees are infrequently called to the task by patients or their families. Usually, it is the weary or frustrated health-care team that finally calls in the ethics committee or asks for a consult. The call (or, more accurately, the absence of a call) for the services of bioethicists from patients, families, and other nonprofessionals should be a humbling recognition.

Ordinary people make critical health-care decisions without mastering the nuances of how to apply Kant, Mill, or Rawls, or even Beauchamp and Childress, to their situations. Moreover, they seem no worse off for their ignorance. What should we make of this? One lesson might be that we in bioethics have no corner on good problem-solving processes and skills. Most of us have never claimed moral expertise in the sense of knowing what is right and wrong, but only the more modest knowledge of process—the maneuvers, strategies, and questions that are helpful in ethical decisions, or, in the more strident terms of the ASBH report, the competencies and skills "necessary" for bioethics consultation. Yet perhaps this more modest claim is also an expression of hubris. A more humble and accurate assessment may be that we bioethicists do know something that can be of value to ordinary people making their health-care decisions, *and* that they know useful things as well. Competencies are not professionally sequestered but distributed across persons in a more democratic way, in a way similar to what William James argued for religious experience. We in bioethics

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do, of course, have things to offer, but our training and preoccupations do not usually provide an understanding of the varieties of moral wisdom that inform the decisions of ordinary people. It would be foolish to underestimate the importance of this gap in our training and experience, and worse still to assume that no such extra-professional wisdom exists.

If this is an accurate portrait, then bioethics consultants, committees, and researchers should employ a mode of engagement that invites reciprocity rather than discourages it through the self-congratulatory listing of our "core competencies." The competencies that prove to be core may be quite different from those listed in the ASBH document or mastered in any of the graduate degree programs in bioethics or the short courses and workshops that consultants ordinarily attend. The languages of ethical experience are many. Bioethicists do their work well when they seek translation across spheres of experiences rather than take their native tongue as the privileged or universal language into which the wisdom of others must be translated.

But perhaps this line of inquiry is unfair to bioethicists and the skills and knowledge they possess. After all, ordinary people might want more consultations if they knew what they were missing. Perhaps the more appropriate test is whether bioethicists would want their own services. For example, if I were a hospitalized patient lacking decisional capacity, would I want someone like me called in to help resolve a dispute between my physicians and my family? Well, maybe, but the answer is by no means clear. Many of the qualifications I would want in a bioethics consultant would be idiosyncratic, specific to me and my situation, and might even be disqualifications in the eyes of a certification committee.

Suppose it is my spouse who is hospitalized and no longer decisionally capable. Would I want a team of my bioethics colleagues advising her physician, or me, at some critical decision point in her care? I could name some of my colleagues at Chapel Hill and at other institutions I would very much like to have nearby, and several others I definitely would want to keep at a distance. But would I want the desired colleagues present as ethics experts, or as sympathetic friends and trusted counselors whose opinions matter to me? Clearly the latter. And not

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because I feel I could be my own ethics consultant. Rather it is because what I would need in order to reach a decision that I could live with would be not professional ethics expertise, but allies who would support me, listen to my rambling narratives about my spouse, help me remember what is important to her, and decipher the meanings of the choices before me. Perhaps this is what some ethics committees or ethics consultants, at their best, can also do, but it is a tall order to expect this quality of interaction among strangers who meet in a crisis.

My examples are meant to underscore not only the usual problems of offering and receiving moral advice, but also the fundamental error in seeking standardization in bioethics, even when the standards are presented as "voluntary guidelines." Moral reflection and deliberation are always local, always the reasoning and reflection of some person, nested in some community, at some point in life's journey, not a replicable process that can or should proceed in a uniform way. This does not imply that there are no useful general principles or values, but rather that the trick lies less in knowing what these principles and values are and more in how to order them, decipher their meaning, and apply them with insight in varying circumstances. What enables persons to make wise decisions is a perspicacious grasp of their situation as well as a complex of virtues like courage, honesty, responsibility for self and others, hope, and other values peculiar to each person. Ethical competence rarely resides in the ability to place oneself behind a Rawlsian veil of ignorance, or legislate universally as Kant would have us do, or accurately calculate Benthamite pleasures or utilities. Although these maneuvers might be useful, they have no more intrinsic value than talking to one's sister, praying, or any of a myriad other strategies that could put a person in touch with his or her own values in a self-conscious and critical way. Moral decisions are concrete, specific, and personal, not abstract, general, or impersonal. Moral decisions are also inevitably social, affecting and affected by others, but nesting decisions in a social context does not render them impersonal; it simply adds to their particularity and distinctiveness. Decisions belong to the moral agent, as pots to the potter, and to seek to judge from one's own

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authentic point of view is usually a mark of maturity rather than a flaw in reasoning.

If bioethicists have a moral competence that has social value, it does not lie in the mastery of some standard or normative way to decide, to facilitate decisions, or to promote consensus, any more than it lies in knowing what the right decisions are. The competent bioethicist is most likely simply the person who knows how to locate persons and their moral reasoning in the full and appropriate context, thereby displaying more clearly their meanings. Again, the contributors to the report might say that this hermeneutical capacity is just what they were trying to get at in the list of core competencies. If so, they have failed, for exercising an interpretive skill in the wide social and moral pluralism of the United States means eschewing the core.

ADDRESSING THE WRONG PROBLEMS

Another issue germane to the social purpose of bioethics arises not from dealing with problems in the wrong way but from dealing with the wrong problems. A history of bioethics could be written based on an analysis of the kinds of problems bioethicists have found worthy of their attention. Prominent in this list would be securing decisional prerogatives for patients in the face of the long tradition of medical paternalism; promoting respect for human subjects and reducing harm and abuse in medical research; and (to a lesser extent) improving access to health services for the growing number of uninsured. These are all important problems, and perhaps it is not too immodest to claim that bioethicists have had some influence in the first two areas, replacing medical paternalism with patient self-determination and serving as a constructive force in the establishment of more rights and protections for research subjects. Advocacy for a fair system of health care, however, has failed miserably, at least so far. But more disconcerting than this failure is the shift in bioethical energy over the past five years toward repairing the moral lapses and gaps in managed care, which are primarily a problem for harried physicians and insured-but-anxious middle-class citizens.

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What could be wrong with this focus on managed care? Perhaps nothing, in itself, just as there is nothing wrong with bioethicists working on problems such as the transplantation of nonvital body parts or the retrieval of sperm from the comatose and newly dead. Yet there are substantial opportunity costs when energy and talent are deflected from major social problems toward issues that affect only a few affluent individuals. More importantly, helping managed-care corporations with their public-relations problems, helping physicians feel less conflicted about managed care, or helping the insured to tolerate it better—or, alternatively, to bend managed care to their demands by advocating for a "Patients' Bill of Rights"—may well weaken the sense of affinity and common cause among doctors, the insured middle class, and the growing underclass of uninsured people. We may not simply be working on the wrong set of problems but, by helping to solve them, hampering work on the larger problems, in this case making more remote the day when universal coverage will be politically viable. Implicit in this analysis is the range of our sympathies—questions of *whose* problems we take to be important enough to merit our time.

What are the right problems? First on my list would be the disgrace of a health-care system that rations access by ability to pay. As Uwe Reinhardt puts it, in America our national policy is that a child from a poor family has a far smaller chance of receiving medical help and of being protected from preventable disease than a child from a rich family.[17] But perhaps a deeper problem for bioethics as a field is that this problem does not seem to keep us awake at night any longer or engage our most creative energies.

In another sense we might determine what problems are the right ones to work on by trying to assess areas in which suffering is the most profound or widespread.[18] Wherever that is—in the lives of impoverished children, in persons with chronic and debilitating diseases, in the terminally ill, in institutionalized elderly populations, perhaps in migrant families—that is where our energies should go. Whatever the outcome, it would be a sign of our professional health to have an extended public debate on just where our energies are best spent. Our deepest

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fear in bioethics should be not that we will prove to be inadequate to the task and fail, but that we will succeed with trivial problems. Playing for small stakes, especially as we gain legitimacy and social authority, should be a source of embarrassment.

ETHICS FOR SALE

Little notice has been given to the way bioethics is being influenced by the commercialism in health care.[19] In the current environment, doctors are no longer physicians but "providers"; sick persons are no longer patients but "members" or "customers"; managed-care organizations tout their high marks on "consumer-satisfaction surveys." Going to see the doctor is now customarily portrayed as purchasing a product or making a claim for a service previously contracted, rather than seeking help from a trusted professional. Market commercialism and the commodification of health services are in full ascendancy. Do we think that doctors can lose their professionalism but bioethicists will not, that health care can become commodified and bioethics will not?

One index of the change is how a central concern of bioethics, namely, choice, has been altered. Seeking to assure a greater range of autonomous choices for patients and research subjects has been a consistent theme of bioethics. Here choice has to do with the exercise of values central to the patient or subject, with the understanding that a patient's or subject's values may differ from those of the physician or researcher, or from institutional priorities. In the current climate, however, choice has a consumer connotation, and freedom to choose is portrayed as a virtue associated with markets in a commercial transaction paradigm. Recent trends have confirmed the critique of John Berger that markets have come to replace political and social-service institutions.[20] Being a savvy consumer and participating in the vast engine of capitalism have become a substitute for being a citizen who participates in the public realm of democratic life, or participates in the more private realm of health care by delivering and receiving professional services. Instead of voting and serving, we shop and negotiate, and it is in the

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transactions to obtain and then consume market goods that we make our fundamental choices and shape our identities.

This commercial notion of choice was becoming evident in medicine even in 1988. In a *New England Journal of Medicine* essay entitled "Morality for the Medical Industrial Complex," the authors noted that one of the usual criticisms of the commodification of health services is that it is thought to erode ethical values.[21] In response, they argue that market forces can enhance ethical values. We can and should market ethics, they say, just as we market technical services. Patients want kindness and their rights respected, and they will be willing to pay for these things. Practitioners, they argue, will have an incentive for high moral standards, and those who maintain these standards will have a market edge.

In one sense, Engelhardt and Rie are correct. A reputation for courtesy, honesty, and fair dealing is an advantage in attracting patients to physicians and health-care organizations, just as these qualities attract consumers to certain retailers. Yet, in another sense, the portrait of medical ethics as completely congenial to the norms of marketing is inaccurate and troubling. Packaging ethical relationships as a commodity to be used to commercial advantage runs directly counter to the idea of a professional ethic as an intrinsic and nonnegotiable core. The purpose of affirming a set of ethical standards is to have moral benchmarks that are *independent* of market forces, indeed, independent of any other forces that might compromise quality of care. Marketing ethics makes it another item on the medical consumer checklist rather than an inherent good that can be counted on despite fluctuations in the customer's purchasing power or the provider's profit motives. Moreover, a basic physician ethic is one of the key stabilizing ingredients that can free patients to exercise meaningful choices in their own care. When this basic ethic itself becomes a consumer option, a fundamental patient liberty—liberty to be candid and open with a trusted fiduciary—is undermined. The need for trust, based on the accentuated vulnerability of patients, is one of the critical points at which medical and business ethics diverge.

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If commercial idioms have become the dominant language through which we judge the adequacy of health services and through which we seek a rationale for the way the health-care system operates, bioethicists will hardly be immune. We are increasingly likely to be judged by how much marketing value we contribute to a health-care package. This has vast implications for our fledgling attempts to claim a degree of professionalism for our work.

I noted earlier that most of the referrals in bioethics consultation come from institutional staff. In a real sense, ethics consultants and committees are assigned their work largely by those who pay for the work. From a purely business perspective, this makes sense, but it can have a dampening effect on the effort of bioethicists to locate and analyze problems outside this customary pattern of referrals. Without an extra-institutional perspective, ethics committees and consultants will simply confirm the worst suspicions of patients and their families that ethics committees function as a way to encourage compliance and reduce litigation.

Carl Elliott, writing on the current confusion about the proper goals of medicine, says that the crucial question to ask in a capitalistic medical-care system is not where the trucks are going, but who is paying the drivers. In the absence of an agreed-upon destination, "The trucks go mainly where the drivers are paid to go."[22] It would be naive to think that bioethicists can remain free of a similar judgment without a far more robust and expansive sense of our professional responsibilities.

WHICH PUBLIC? WHOSE GOOD?

One of the defining characteristics of professionals is that they have at least one eye on the public good; that is, they use whatever socially useful knowledge and skills they possess for something more than personal gain. For professionals, self-interest is always moderated, and sometimes superceded, by considerations of public interest. Most bioethicists are involved in some sort of larger public engagement, something in addition to specialized research projects and classroom or seminar teach-

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ing. Many are involved in formal consultation services, and almost all at least occasionally work with health professional colleagues in clinical settings and serve on institutional review boards, data and safety monitoring boards for research projects, and ethics committees. Yet this sort of public engagement, even when done with great skill, affects only a privileged sector of the society, and the goods sought still tend to be parochial rather than public. Bioethics needs a more expansive vision of itself, not only as shaping and shaped by the clinical work of health professionals and the policies of hospitals and health-care institutions but also as shaping and shaped by the concerns and needs of the ordinary citizens I spoke of earlier. I argued above for reciprocity in the recognition of moral skills and knowledge. What is also called for is a reciprocity in perspectives and purposes, a collaborative understanding of which problems are important and what will count as a "good" outcome for ethics work. The recognition of limited expertise and need for reciprocity with the public highlights questions of *which* public we are to be engaged with, and *whose* good should direct our goals.

Ezra Pound put it aptly in his *Cantos:* "not as land looks on a map but as sea bord [*sic*] seen by men sailing."[23] E. A. Vastyan quoted this line from Pound in his 1981 address to the Society for Health and Human Values, the oldest and largest of the predecessor organizations that united to form the ASBH. Vastyan used this phrase to signal the direction he believed the field of medical humanities should be moving, namely, away from academic theory-building and credentialing and toward an enhanced ability to empathize with and understand the humanity of patients and those who care for them.[24] Enhancing this ability means entertaining more readily and fully the perspectives of those at sea seeking a safe harbor rather than the perspectives of professionals, administrators, and system organizers viewing representations of reality from high altitudes.

The conception of bioethics as a profession engaged in the pursuit of this broader public good (not merely self-interest, and not simply narrowly defined notions of the good) carries major implications for how bioethics work is assessed. On the terms of this expanded vision, bioethicists would be mistaken to judge

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themselves solely by how well they replicate standard academic norms of excellence or medical norms of competence. The additional register is whether bioethicists can engage the larger public (or various publics) in asking critical questions about the moral values encountered in health care and, in turn, come to understand these public engagements as a defining feature of their professional success or failure. This more academically humble but socially ambitious version of bioethics would recognize that problems in reaching consensus in clinical contexts may stem less from using the wrong theory or process and more from failure to deal with class and socioeconomic differences, especially with the distrust that ensues from tolerating for so long the vast differences in health access and status that are based on these differences. Bioethics as a form of public professionalism would also acknowledge that problems in healthcare reform are due less to the lack of a convincing theory of equality and more to the fact that as a society we have never learned to engage in sustained dialogue about value differences in a civil and productive way. Finding ways to sustain and nurture that dialogue is part of the professional mission that bioethics should assume.

CONCLUSION

In describing how commercial managed care has undermined public trust in physicians, William Sullivan asserts: "It is hard to see how medicine can resolve its crisis of legitimacy without simultaneously seeking to redefine its identity around a public mission."[25] Although it is still emerging as a field and has yet to attain anything like the public regard that medicine once enjoyed, bioethics is in the same precarious situation as medicine.

Are we professionals? Here is my set of questions that would need to be answered in the affirmative for this to be so.

Do we understand our social acceptance as an obligation to advocate for change? Being a professional means having something to profess. We live in a society of great abundance, yet our political traditions tolerate the maintenance of a healthcare system with vast and growing levels of uninsurance and underservice, a system that excludes nearly 45 million citizens.

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Other modern democracies consider a system that tolerates this sort of inequity a failure. So should the United States. Bioethicists must play a part in bringing to political fruition a remedy for our increasingly brutal health-care policies.

Are we spending our energies on problems that matter? Are we actively creating our own agenda for work? Being a professional means having an independent judgment about which issues are important. Being responsive to issues in our local institutions is necessary and appropriate but should not exhaust our sense of what work it is important to pursue. One item on our self-imposed problem list should be the increasing commercialism of American health care, including its impact on how medical and health sciences students are educated as well as the diminished role of professionalism for all of us when market norms for health care go unchallenged. Instead of courting managed-care organizations for advice on how to better train our students to function efficiently in a commercial environment, we should be engaged in making sure that our graduates know how to distinguish between a sound managed-care contract and one that is morally perverse.

Do we accredit and learn from the moral wisdom of a wide variety of other persons? Being a professional means possessing a healthy agnosticism, having a sense of the limits of one's own competence, and not claiming knowledge one does not possess. This means eschewing chauvinistic claims and assumptions that bioethicists possess something unique and essential for ethical decisions or deliberations. The only way to assure that the temptation to claim special competencies does not distort ethical teaching, consulting, and research is to remain open to the multiplicities of moral wisdom found not only in our colleagues but in ordinary people. One thing this requires is a far better grasp of how religious rituals and practices (not merely theological doctrines) inform ethics.[26] Such openness will help to ground our work in our own humanity, instead of in some special skill set or competence. Such a grounding does not deprecate formal academic training in ethics, but anchors it in the larger sphere of human moral experience.

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ENDNOTES

[1]This definition is a slight variation of the one offered by Simon Blackburn in *The Oxford Dictionary of Philosophy* (New York: Oxford University Press, 1994), 44.

[2]David Hume, *A Treatise of Human Nature* [1739–1740] (Oxford: Oxford University Press, 1978), 272.

[3]Tom L. Beauchamp and James F. Childress, *Principles of Biomedical Ethics* (New York: Oxford University Press, 1994), 23ff.

[4]Larry R. Churchill, "Bioethical Reductionism and Our Sense of the Human," *Man and Medicine* 5 (1980): 229–242.

[5]Larry R. Churchill, "Bioethics in Social Context," in *Philosophy of Medicine and Bioethics,* ed. Ronald A. Carson and Chester R. Burns (Dordrecht: Kluwer Academic Publishers, 1997).

[6]American Society for Bioethics and Humanities, *Core Competencies for Health Care Ethics Consultation* (Glenview, Ill.: American Society for Bioethics and Humanities, 1998).

[7]Ibid., 8.

[8]Ibid., 6–21.

[9]Ibid., 31–32.

[10]Ibid., 1.

[11]The American Society for Bioethics and Humanities was formed in 1997 as a merger of three existing organizations: the Society for Health and Human Values (SHHV); the Society for Bioethics Consultation (SBC); and the American Association of Bioethics (AAB). The *Core Competencies* report is the culmination of work originally begun by a task force formed by the SHHV and the SBC.

[12]*Core Competencies,* 32.

[13]Nancy M. P. King, "Who Ate the Apple? A Commentary on the Core Competencies Report," *Healthcare Ethics Committee Forum* 11 (1999): 170–175.

[14]William James, *The Varieties of Religious Experience* [1902] (New York: The Modern Library, 1999), 33.

[15]Ibid., xiii.

[16]Ludwig Wittgenstein, *Philosophical Investigations,* trans. G. E. M. Anscombe (New York: The Macmillan Company, 1953), 31e.

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[17]Uwe E. Reinhardt, "Wanted: A Clearly Articulated Social Ethic for American Health Care," *Journal of the American Medical Association* 278 (1997): 1446.

[18]Some scholars have made suffering a central focus of their work. See, for example, Eric J. Cassell, *The Nature of Suffering* (New York: Oxford University Press, 1991); the Winter 1996 issue of *Dædalus,* "Social Suffering" (Vol. 125, No. 1), republished by the University of California Press, ed. Arthur Kleinman, Veena Das, and Margaret Lock; or Erich H. Loewy, *Suffering and the Beneficent Community: Beyond Libertarianism* (Albany: State University of New York Press, 1991).

[19]Yet see the interesting essay by Carl Elliott, *A Philosophical Disease: Bioethics, Culture and Identity* (New York: Routledge, 1999), 1–23.

[20]John Berger, *Ways of Seeing* (London: Penguin, 1972).

[21]H. Tristram Engelhardt and Michael Rie, "Morality for the Medical Industrial Complex," *New England Journal of Medicine* 319 (1988): 1086–1089.

[22]Elliott, *A Philosophical Disease,* 23.

[23]Ezra Pound, *Cantos* (New York: New Directions Publishing Co., 1956), 70.

[24]E. A. Vastyan, "Healing and the Wounded Healer," address to the Society for Health and Human Values, Philadelphia, 1981, 14ff.

[25]William M. Sullivan, "What is Left of Professionalism after Managed Care?" *The Hastings Center Report* 29 (1999): 7–13.

[26]My distinction between rituals and practices on the one hand and theological doctrines on the other is similar to Clifford Geertz's distinction between an "ethos" and a "world view." See Clifford Geertz, *The Interpretation of Cultures* (New York: Basic Books, 1973), 127ff. A culture's ethos is its moral and aesthetic tone and character, while the world view of a culture refers to its explicit picture of the way things are. Geertz describes the interaction between these two components as mutually reinforcing: the ethos makes the beliefs of the world view emotionally acceptable, while the world view gives the ethological practices intellectual accessibility and authenticity. In a similar way the prayers, rituals, and emotional valences of religious life interact with theology, not simply mirroring the theological picture, but providing the nurturing source for at least some of the ethical convictions of believers. Therefore, understanding the ethic of religious persons means understanding how that ethic is grounded in the customs and practices of the ethos. Efforts to converse with religious persons through an exclusive focus on their theological beliefs (or world view) only show our ignorance of what ethics is and how it functions.

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Daniel Callahan

The Social Sciences and the Task of Bioethics

IT TOOK ME SOME YEARS to realize the obvious. Ethics is a peculiar enterprise: a professional discipline for some, a matter of uncertainty and even suspicion for others, and for most people something they are, like it or not, supposed to take seriously. Now and then there is a burst of interest in teaching ethics to schoolchildren, but it is always mixed with ambivalence. Is that not the role of families, not government? And whose ethics should be taught, anyway? Meanwhile, courses on ethics have proliferated in universities, even though debate on their purpose persists. Is their aim good behavior, a virtuous life, or sharp ethical analysis?

Bioethics, as a new subdiscipline, shares a similar mixed fate. It has become a popular subject in colleges and medical schools and a hit with the media. Even so, there is a lingering uncertainty about its purpose and value. Some of us are called bioethicists, a term that was just beginning to come into use thirty years ago and that does not tell us exactly what it is we are supposed to be doing. Though their number has diminished over the years, more than a few physicians are wary of outsiders, especially philosophers and lawyers, helping them do the right thing. Meanwhile, the federal government, faced at times with ethical hot potatoes of a kind that riles legislators and inflames moral zealots, has responded by establishing no less

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than three national bioethics commissions over the past twenty-five years. Only a minority portion of the membership of those commissions has consisted of bioethicists, revealing perhaps a belief either that ethics is too serious a matter to be left to ethics experts—true enough—or that anyone of sound mind and randomly chosen credentials can fill the bill—not quite so true. Charles Lindblom has remarked that political scientists cannot offer many surprises to students, "for their world and ours is the same familiar world."[1] The same can be said of ethics: everyone knows something about it, and those of us who are alleged experts may have no better insights, and maybe even less useful experience in our own lives, than ordinary people.

Though I cannot resist at times an ironic tone when speaking of my own field, one reason is simply this: I take bioethics seriously, but it provokes, by turns, pleasure, amusement, dismay, and regret. I suspect that is because the field is so riddled with many of the broader problems of American culture that it invites a muddle of major proportions, not easy to escape and usually implicating us in that culture even as we try to step out of it. The social scientists have been telling us this for years, not always in a kindly manner, and we are now listening.

My aim here is to respond to that nudging and at the same time to hold tight to some steady convictions, which can be stated baldly enough. Bioethics has as its main task the determination, so far as that is possible, of what is right and wrong, good and bad, about the scientific developments and technological deployments of biomedicine. What are our duties and responsibilities in the face of those developments?

If one traditional aim of ethics has been to discern what it means to live a good and worthy life, then bioethics should aim to cultivate those virtues and sensibilities necessary to do so in the context of biomedical ends and means. If another aim has been to help people determine how to make good ethical decisions, then bioethics needs to carry on this work in the biomedical setting. If ethics has, along with political philosophy, sought to discover the nature of the good society, then bioethics must seek to determine which of the scientific developments and their practical application best contribute to that goal.

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The argument is commonly made that, in a pluralistic society, ethics should try to cultivate a respect for communities of conviction and belief that are not the same as ours. Ethics should, it is said, aim for social peace. I will not quarrel with those worthy aims, but there is another side to that coin: it is no less important to oppose forthrightly cultural values and moral convictions that do not withstand the scrutiny of fair and careful judgment. Life in a pluralistic society is full of flux. We move around socially, coming and going in our moral lives. We are called upon on occasion to scrutinize our own community, to know when to call it to account if it fails to do what is right, and to leave it if necessary. We are no less called upon to determine what standards to use in choosing another community, and to ascertain which communities and patterns of belief and moral practice are worthy of respect and which must be resisted or rejected. Some broad standards are necessary to do this, standards not dependent for their worth on the blessing of the very culture requiring judgment.

Most critically, in a society that enshrines liberty as its highest value, the great moral question is how most responsibly to use that liberty and to do so from some vantage point that allows us to rise above our own self-serving impulses. It is, moreover, hazardous to do as our society so often likes to do, to make a sharp distinction between public and private morality, implying that the former can be firm and demanding (no racism, sexism, etc.) while the latter is subjective, open to no binding moral judgment. But it has never been clear to me why the public and private sphere ought not to be equally subject to ethical inquiry, even though the norms might be different.

None of these aims make much sense if one is not willing to entertain the notion that there are some universal human goods and truths that can and must be called upon to rise above the particularities of culture. The hard part is to determine when to do so and when not to do so. It may be true, as one anthropologist has noted, that the "nature of moral thought and action" is "culturally constituted."[2] But that does not tell us very much about the validity of ethics as a form of intellectual inquiry or its capability of either moving beyond its cultural roots or helping us to discern whether an ethics identified with one

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culture can be usefully carried to another. The latter happens now all the time.

To think well ethically requires three skills, each of which requires cultivation. The first is knowledge of the traditions of ethics, religious and secular, as well as the formal theories and strategies that historically have been deployed to analyze ethical issues. The second skill is social perceptiveness: the capacity to understand our own culture and the way it has tutored us with certain values and patterns of thought and behavior. The third is self-knowledge: the ability to grasp our biases and proclivities, to resist self-deceit, to note our moral weaknesses and failings.

THE BIOETHICS ENTERPRISE

Those are my general premises. What do they mean for the pursuit of bioethics, and just what is the nature of the discipline? Bioethics can surely be spoken of as a child of the 1960s, even if less wayward and more establishmentarian than some of the other children.[3] Four developments were important: the opening up of once-closed professions to public scrutiny, which happened strikingly with medicine; the fresh burst of liberal individualism, putting autonomy at the top of the moral mountain; the brilliant array of technological developments in biomedicine, ranging from the pill and safe abortions to control the beginning of life to dialysis and organ transplantation to hold off the end of life; and the renewed interest within philosophy and theology in normative ethics, pushing to one side the positivism and cultural relativism that seemed for a time in the 1940s and 1950s to have spelled the end of ethics as a useful venture.

While much of the social-science critique of bioethics has focused on its abstract concepts, its stance of detached objectivity, and its search for universal principles, that is not the whole story. As anthropologists dedicated to "thick description" will certainly note, even among those who espouse "principlism"—an oft-designated villain in bioethics—there is a lively awareness of its problems and liabilities.[4] It is helpful, however, to understand that bioethics has much diversity these

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days—feminist, communitarian, contextualist, casuistical, for example—and many strands, not all of which require a search for sweeping universals or eternal principles.

I have found it helpful to classify these strands as follows: there is *clinical bioethics,* aimed at analyzing the moral problems and dilemmas of bedside medicine and discerning the virtues appropriate for the care of patients; *foundational bioethics,* exploring the ethical basis of bioethics and its relationship to the broader field of general ethics; *regulatory bioethics,* helping to fashion laws and regulations for public-policy purposes; *cultural bioethics,* striving to determine the cultural basis and implications of biomedical advances; and *health-policy bioethics,* whose purpose is to propose a just management and allocation of health-care resources.

Frequently enough, there is an overlapping of these strands. The care of the terminally ill is a matter for clinical, regulatory, and cultural bioethics, and, if there is a worry about the fair amount of resources that should go to the dying, it is a health-policy issue as well. Assisted reproduction techniques, whether cloning or *in vitro* fertilization, cut deeply into the nature of procreation, childbearing, and family life and thus have profound cultural implications; the debate over the banning of efforts to clone a human being makes it a matter for regulatory bioethics. The problem of universal health care is clearly pertinent to health-policy ethics, while the failure of the United States to provide such care when every other developed country has it is fair game indeed for cultural analysis. Organ transplantation forces difficult questions about bodily integrity, the gift relationship, and the allocation of scarce resources.

The more interesting story perhaps concerns the culture of bioethics itself. It is a discipline with some discernible biases, some unmistakable signs of its heavily American origins, and some long-standing internal struggles. While it is possible to spot the influential hand of philosophy in the field, it is strongly interdisciplinary, dominated by a troika of medicine, law, and philosophy. In its early days, during the late 1960s and early 1970s, when bioethics was beginning to be distinguished from the historically ancient field of medical ethics (more narrowly limited to physician integrity and collegiality), theology was the

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dominant discipline. As the field became more secular, adapting itself to the vernacular of public-policy discourse and led by philosophers and lawyers, religion was pushed to the sidelines.

Though I am not myself religious, I consider the decline of religious contributions a misfortune, leading to a paucity of concepts, a thin imagination, and the ignorance of traditions, practices, and forms of moral analysis of great value. An explanation of that judgment is needed. In its earliest days, there were two powerful currents in bioethics, not necessarily incompatible but surely moving in different directions. One of them turned its attention to individual rights and choice, with which the analytically trained philosophers and lawyers were most comfortable, and the other to the social and cultural meaning of the biomedical developments, which profited from a religious and social-science presence as well as nonanalytic philosophical approaches.[5]

The former of those currents was instigated by the struggle over human-subject research, at that time marked by many abuses, of which the Tuskegee scandal was the most notorious. That struggle brought to the foreground questions of informed consent, the rights of research subjects, and the need for a regulatory apparatus to oversee hazardous biomedical research. It was not a long step from that concern to a broader critique of the characteristic paternalism of the doctor-patient relationship, the generation of a patient rights movement, and the triumph of autonomy as the most prized patient value in an up-to-date practice of medicine (and from there, willy-nilly, to talk of the doctor as "provider" and the patient as "consumer"). That shift was compatible with the emergent reproductive rights movement, symbolized by the 1973 *Roe* v. *Wade* abortion decision, and quickly extended beyond abortion rights to a wider set of moral claims insistent on the unimpeded access to all forms of assisted reproduction. It is perfectly possible, of course, to accept the idea of patient rights and to reject the claim of a right to abortion, but in practice they have come as a package, at least in the mainstream of bioethics.

The other current, social and cultural in its thrust, saw the main role of bioethics as an exploration of the likely effects of biomedical knowledge and its application on the human condi-

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tion: the appropriate role of biomedicine in promoting human welfare and sustaining such important institutions as the family and community, the way health as an individual and societal good is to be understood in the context of other human needs, and the way we understand human nature and human dignity. Bioethics was meant to be grounded in a broad examination of all the larger problems of the meaning and purpose of human life.

The term "human dignity" is a special tip-off here. Kant was willing to entertain it, and its use is common in European bioethics and legal conventions. But it is typically scorned by secular-minded American bioethicists, thought to be too vague to be useful and too weighted with the baggage of religion to be safely used in a pluralistic society. It suggests as well a dreaded essentialism—that human life might have some inherent value—about which not enough bad things can be said by anti-speciesists, evolutionary biologists, and some single-minded philosophers. Religion itself is sometimes feared as a social force in bioethics debates, associated (of course) with right-wing politics, sectarianism, and obscurantism. Only reason, clean, pure Enlightenment reason—free of the contamination of emotion, ideology, and culture—is acceptable for much of bioethics, even if its more recent fate in philosophy has been to drift downhill.

For those social scientists who have deplored the dissociation of bioethics and questions of human meaning—a critical part of the cultural life of most societies—the move of bioethics away from religion is a good place to look for its origin. Religion is all about the meaning of life. The old joke I heard as a graduate student in analytic philosophy some years ago is not all that dead: "life doesn't have a meaning; only propositions do." One will search in vain in the bioethics literature for any full and rich effort to connect questions of meaning to questions of ethics. Not incidentally, its failure to find a place for religious thought is one reason that bioethics does not find, despite national commissions, the kind of resonance in Congress that it might. Its resolute secularism is out of step with much of American culture, even though it picks up (all too much) the individualism of that culture (just as, interestingly, the market ideology of for-profit medicine does).

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The goal here is not just to make a place for religion, though that seems only pluralistically fair and intellectually sensible to me. It is instead to find room for a capacious view of bioethics, one that allows it to dig more deeply into the way biomedical progress can restructure the living of a life and the possible meanings that can be given to life. Just what should be counted as genuine human progress as distinguished from mere change and innovation? Effective contraceptives not only provide more reproductive choice; they have changed the role of women, the male-female relationship, and the size and structure of families. Increased longevity past the age of sixty-five does not just add years to life; it is giving those years, when healthy, a new significance—and along the way promising to wreak havoc with the Medicare program in the next few decades, forcing a fresh appraisal of one of the oldest of moral obligations, that of the duty of the young to the old.

I am not claiming that bioethics utterly fails to address those larger questions. My point is instead that they tend to take a decidedly second place to regulatory problems and to matters of individual preferences and rights. An analogy may make my point clearer. For some years now there has been an interesting discussion about the most useful way to understand the origins of disease and the scope of medicine. One view, seeking to understand the biological (and, most recently, genetic) roots of illness and disease, has been called analytic and reductionist. The competing view, rejecting reductionism and called biopsychosocial (or some similar name), has wanted more expansively to encompass the social and environmental sources of disease, not simply its biological origins.

Bioethics has its own form of reductionism, and it has dominated, though not wholly conquered, the field. That reductionism has been stimulated by the regulatory interests of courts and legislatures, by the regnant understanding of pluralism as requiring accommodation, not challenge, and by the omnipresent value of liberal individualism. It has taken the form of a search for three key elements of a socially useful bioethics. They are a set of simple principles that will help to resolve difficult moral dilemmas; fair and reasonable procedures to deal with ethical disagreement; and, when individual good and

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common good come into apparent conflict, a systematic way to give the benefit of doubt to choice and freedom rather than to restraint and community.

As the leading theory in the field, principlism has been the main reductionist agent. In promoting the principles of respect for persons (generally understood as respect for autonomy), nonmaleficence, beneficence, and justice, it has proved enormously attractive, both in the United States and, increasingly, in other countries as well (something the social scientists have not much noticed). It offers a seemingly clear method for doing ethics, and it involves relative theoretical simplicity.

I call it reductionistic for two reasons. The first reason is evident enough: four principles, and only four, are thought sufficient to deal with the main run of ethical demands and puzzles. The second reason is less evident: the driving force of principlism in practice is autonomy. Why? Because the principle of nonmaleficence is simply a derivative principle from that of respect for persons and their bodily sovereignty; justice as a principle is to be pursued so that, in the end, individuals have equal opportunity to pursue their autonomous life goals without an unfair lack of access to good health care. In practice, the principle of beneficence gets the least play, probably because, to be taken seriously, it requires an effort to understand what really advances the good of individuals and society. But that kind of effort runs afoul of the liberal individualism of the left and the libertarianism of (some of) the right, both of which hold that there is—following, say, Isaiah Berlin—no such thing as "the" good of individuals or "the" good of society. There are many possible goods and it is up to individuals to choose their own. It is hardly surprising that those who have most systematically taken up the principle of beneficence come to bioethics from a religious angle.

The reductionist drive of principlism has had some debilitating effects on the field. One of them has been to make ethical analysis easier than it actually is, offering a kind of handy shortcut to the making of decisions (which may also explain its attraction to busy physicians who are looking for more simplicity, not more complexity, in their clinical lives). The other effect has been to block the pursuit of old and important ethical

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questions. It is the right to choose, not the content of choice, that counts. But are all reproductive choices, for instance, good just because they are legally free and autonomously chosen? Is the good of individuals nothing more than allowing them their self-chosen preferences (such as physician-assisted suicide)? If nonmaleficence is understood only to be the avoidance of medical harm to persons, how are we to judge the potential harm to institutions and to valid forms of social and family life that medical advances might bring (such as the choice of the sex of one's child or systematic research efforts to greatly extend the average human life span)? At its worst, ethical reductionism dotes on the language of rights, wants clean and uncluttered principles, and flees from pressing larger questions of the relationship between medical possibilities and long-range human welfare, matters thought best dealt with (if they cannot be avoided) procedurally rather than substantively.

Now, having let off a bit of steam about principlism, I need to acknowledge its force and cultural bite. It has been accepted in great part because it is so compatible with American culture, at least that well-rooted liberal part of the culture that has looked to law to resolve, or dilute, deep moral disagreements, and which bends over backwards to allow citizens the widest range of legal choices and the greatest possible latitude in the living of a life. The language of rights is more comfortable in America than the European language of solidarity—which helps explain why we have market-dominated health care rather than a Canadian- or European-style universal health-care system. A project I directed on the goals of medicine fared much better abroad than at home. The language of "goals" too often brings out a rash among Americans. Bioethics is often too American, too culture-conforming, too prone to float along with the tide.

THE SOCIAL SCIENCE CRITIQUE

As my comments about bioethics should suggest, I am by no means happy with the general direction it has taken. It seems to me to have accomplished much less than it should have and gone down many sterile side paths. My own recourse to a

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cultural analysis of the field (albeit of my own fashioning) should show that I am amenable to ways of thinking about bioethics drawn from richer veins than provided by my own training in analytic philosophy. Nonetheless, I am uneasy with the contention that the social sciences, and particularly ethnography, offer a better way forward. This may be so, but only if they are combined with a way of pursuing ethical analysis that knows how to make good use of social-science knowledge, whether quantitative or qualitative. Ethics must, in the end, be ethics, not social science.

The social sciences surely offer forms of knowledge pertinent to ethics and parallel to what I characterized above as three necessary ingredients of ethics. Psychology can provide insight into thinking, feeling, and behavior, including the place and role of reason and emotion in shaping moral intention and action.[6] Sociology and anthropology can offer useful methods for understanding culture and the social determinants of values, and they might—though this has not been done so far as I know—have something to say about the contextual setting of different ethical theories that have appeared in recent years. As Alexander Nehamas noted in *Dædalus* in 1997, "some philosophers are beginning to look at analytic philosophy itself as a historically situated moment, not simply as the revolution that for the first time stood philosophy right side up."[7]

Good survey research data can provide knowledge of existing values and moral commitments as well as an understanding of where the public stands on specific issues. Quantitative studies can be used to determine the actual consequences of different public policies with a significant ethical content. My own work on abortion, health policy for the elderly, and the care of the dying has profited from all of those forms of social-science knowledge. I can recall with particular delight an instance of learning something from two anthropologists that I might never have discovered on my own, and surely not from moral philosophy: that medical residents are prone to define death not as the failure of critical bodily organs but as occurring when technological interventions no longer work—death as technological failure.[8]

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Is all of that enough to make the case for the utility of the social sciences for ethics? Not quite. Three hurdles must be surmounted. One is the need for ethically relevant knowledge from social scientists. Another is the parallel need for types of ethical theory that have a way of efficaciously using social-science knowledge. Still another is a way of climbing that most intimidating mountain known as the is-ought fallacy: the belief that a moral "ought" can be deduced from a factual "is." Not so, as most philosophers have held at least since the time of David Hume, who first called attention to it.

There is plenty of ethically interesting social-science information around and much that can still be had. But "interesting" is not the same as "relevant," which requires a theory that can determine what *is* relevant and then knows what to do with it once it is in hand. It surely seems interesting to know that survey researchers have shown the public to be strongly favorable toward physician-assisted suicide. But from an ethics stance one can say, correctly enough, "so what?"—because the public can be wrong, and, in any case, it is invalid to make a move from a public-opinion "is" to a public-policy "ought" (something politicians have always known). Recall that opponents of capital punishment have never been deterred by those polls showing its great popularity with the public. Nor should they be. Historically, the pre–Civil War abolition movement constantly worked against public opinion before making any real headway; moral conviction only slowly came to carry the day. There is, in short, no ethical theory that effectively instructs us about how to make legitimate use of survey research data in making moral judgments or shaping public policy—that is, any known way of moving from an "is" to an "ought" in this domain.

Still, a closer look is in order. Arthur Kleinman, a medical anthropologist, and Barry Hoffmaster, a moral philosopher, have made eloquent pleas for a greater use of anthropological and, specifically, ethnographic knowledge. Kleinman has written that

> In place of universalist or essentialist propositions . . . anthropologists, always more the intellectual fox than the hedgehog, have focused

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> upon the interactions of everyday life, the social hierarchies and inequalities they represent, and the moral issues in which they are clothed. Thereby, anthropologists examine ethics at the intersection of the social logic of symbolic systems, social structures, and historical events. . . . Whereas ethical discourse is a codified body of abstract knowledge held by experts about "the good" and ways to realize it, moral accounts are the commitments of social participants in a local world about what is at stake in everyday experience.[9]

My problem with this passage is twofold. First, many moral philosophers, beginning with Aristotle and continuing through Hume, have not been interested in developing "universalist or essentialist propositions," even though some contemporary philosophers have been. An ethnographic study of the history of moral philosophy, even recent history, would reveal all sorts of local worlds at work and much reflection upon everyday experience (think of Richard Rorty and Martha Nussbaum). The same can be said of many philosophically trained bioethicists. Second, even the most hands-on ethnographers ordinarily want to develop some generalizations about cultures, e.g., "the social logic of symbolic systems." Not everything in a field devoted to particularity can be particular, and Kleinman's provocative thoughts are full of most helpful generalizations.

Indeed, it is difficult *not* to move from the particular to the general. How else can we make some sense of what is observed? Why, then, is it necessarily objectionable when a bioethicist does so? Nonetheless, having said all that, I profit enormously from reading Arthur Kleinman even if, as a moral philosopher, I am not always clear just how to make the best use of what he teaches me. And I cannot help being constantly reminded that he, as an anthropologist, has a different purpose in his research than my bioethical colleagues and I have in ours.

Barry Hoffmaster shares with Kleinman many of the same complaints about bioethics. After offering a pungent critique of efforts to develop general, universal, and necessarily abstract sets of moral principles, and to do ethics from the top down, he offers an ethnographic alternative, working from the bottom up:

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> . . . excursions into philosophical ethics . . . will remain frustratingly inconclusive unless they are complemented with careful, detailed investigation of the background to and contexts surrounding the issues. . . . judgments of bioethics need to rest on more than philosophically respectable "good reasons"—they need to proceed from and manifest an understanding of morality as lived experience.[10]

Yet there are reasons to hesitate here. What does the word "complemented" come to if there is no specified way to bring the "detailed investigation" together with the philosophical need for "good reasons," which Hoffmaster does not entirely dismiss? We are not given that specification. Moreover, what do we do with the "lived experience" of morality once we have it in hand? Hoffmaster does not say, other than to assert that "Moral theory needs to take a new turn . . . [and to] be responsive to the issues posed by morality in context."[11] We are left dangling since he does not say how that turn is to be made.

The philosopher Thomas Nagel has provided just the right rejoinder to this line of thought. Once we have in hand full background information, we can still ask "How should I act, given that these things are true of me or my situation?"[12] Or, as I would put it, once we have done everything Hoffmaster asks of us, what then? How do we incorporate what we have learned into the making of good moral judgments? How do we get from the "is" of "lived experience" to the "ought" of those judgments that require us to act in some justifiable manner?

If we mean, in any event, to take the "lived experience" of morality seriously, it is worth understanding why there has been in recent years a search for some universal principles. The experience of World War II, for instance, gave rise to the United Nations Declaration of Human Rights. One way or another, the casual moral relativism that had been fostered by prewar positivism and amplified by a now passé anthropological relativism had to be combated. The aim of the Declaration and other UN documents was to lay the foundation for an international order that had some universal moral bite. It is true that the Declaration was the product of Western thinkers, and, specifically, a group of thinkers heavily indebted to natural law theory. But it stuck. The fact that the specified rights are

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regularly and outrageously ignored should not obscure the equally important point that almost all nations now pay lip service to them, and that is surely a necessary first step toward a more serious moral commitment and a lever for moral debate.

In the medical ethics of the 1950s, the theologian Joseph Fletcher became notorious for his challenge to all forms of natural law ethics and for his espousal of a radical alternative, "situation ethics," which was to be utterly particularistic and contextual, shorn of all rules and principles.[13] That kind of ethics would seem to satisfy the desire of contextualists for an ethics without universal principles, or, to use Kleinman's phrase, one that mistakenly seeks "transpositional objectivity."[14] But Fletcher did not win much support: ethics cannot be ethics at all unless it offers some guidance in knowing how to identify an ethical problem (which requires some general standards) or to make ethical judgments that would be other than ad hoc, resting on no broad foundations at all. During the same era, positivism was riding high, dismissing all moral language as nothing more than emotive utterances. The notion that there could be universally valid moral principles was as anathema to the positivists as to Joseph Fletcher.

All that was thin gruel, satisfying neither heart nor mind. By the 1960s and 1970s the search for universals was underway once again, and it was in that milieu that principlism emerged. Were there to be no principles or rules at all concerning informed consent to dangerous medical research, or scientific play with genetic modifications and manipulations, or assessments about whether to stop treating low-birthweight babies or to terminate life-extending care of dying patients? Even the most dedicated particularists seem unwilling to go that far, just as the most dedicated universalists are usually willing to admit exceptions to most ethical principles. The recent move by some feminists in a more contextual direction has not led them to say that women's reproductive rights are culturally determined and only true in those local cultures that believe in such rights. Cultures of cruelty and suppression do not get a sympathetic hearing despite whatever testimony might be provided about their "lived experience" of morality.

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In trying to suggest once more how hard it is to fully reject the universalizing tendency of much ethical theory, even if one wants to, I would point to a conflict between the ideas of Kleinman and Hoffmaster that illuminates a tension within the ethnographic camp. Hoffmaster emphasizes, as does Kleinman, the richness and complexity of the ordinary moral life of people, and ethnography is good at explicating that. But Hoffmaster seems to accept that social reality as itself normative: this is the way ordinary people work through their moral problems, and that is just fine.[15] Kleinman comes close to saying the same thing but saves himself by now and then insisting on the need for a critical stance that requires the rejection of some cultural values. He rejects, for instance, "radical ethical relativism"—a position only possible on the presumption that there are some moral standards that transcend and can be used to assess some otherwise accepted values.[16]

Kleinman, moreover, has written that "It is essential to make the critique of individualism central to a cross-cultural approach to ethics."[17] But is that because ethnographers find individualism too ethnocentric, an offense to the discipline? Or is it because (as I would hope) individualism as a dominant guide to the life of any society is morally defective, something that can only be determined by an independent ethical inquiry? I am not certain how Kleinman would answer that question, but it is clear that he has some strong moral convictions of his own on various issues, which he does not seem prepared to attribute solely to cultural bias.

THE TASK OF BIOETHICS

Is there a way out of what seems the central dilemma here? An overriding effort to devise universal principles neglects the complexity of individual moral lives and social circumstances, while an indiscriminate immersion in their particularity allows no room for ethical distinctions and prudential judgments. I will offer some possible ways to get out of this dilemma.

Ethics, I suggested at the outset, must try to develop general principles and some specific rules; that is not all there is to ethics, but it is an important part of it. It cannot otherwise do

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its proper work or offer fully helpful moral guidance and insight. Principles should not, however, be understood as moral trump cards. They are best seen as ways of organizing our moral thought, giving it a shape and formal structure. They are a necessary step in making sense of our ethical intuitions and reflections, the moral folkways of our own culture, and the clash of values that is a mark of pluralistic societies and a multicultural world. Principlism itself has been defended on the grounds that it can be found embedded in American values and institutions, representing part of our own national "lived experience," if you will.

Pluralism forces two demands upon us: (1) that we learn how to appreciate moral convictions other than our own and to see in the interplay of values a moral opportunity for insights not part of our normal repertoire; and (2) that we have some kind of transcendent principles to pass judgment on our own lives and culture—and also, however unpleasant, on other cultures that pose common dangers.

Ethical principles give us a way to carry out those necessary tasks. The task of bioethics is, in that respect, no different from the broader task of ethics itself. Ethical principles should be judged in terms of their organizing power, providing us some focused ways of thinking and some specific moral directions in which to head. Experience may, over time, lead us to modify some principles and reject others. In that sense, the work of ethics never ends. Ethical principles, moreover, provide a foundation for more specific moral rules, the "thou shalts" and the "thou shalt nots" of concrete communities, that seem no less necessary than the principles. No medical research without informed consent (a principle), and no informed consent without an explanation of the research to the subject (a rule). Principles and rules of this kind can be open to modification in specific cultural settings, but not wholly rejected.

The principles and rules also may change from time to time, they may require reinterpretation, and they should for the most part admit of exceptions and qualifications. They are, as is often said, *prima facie* rules and principles, meaning they can be challenged by other ethical considerations. Renée Fox has made a great contribution during her career in helping us understand

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the importance of medical uncertainty. No one is prepared to reject medicine because it cannot get rid of that uncertainty. Bioethics is no less filled with uncertainty, and, as in medicine, the real test is the way uncertainty is handled. An unwillingness to confront it leads to evasion and rigidity in bioethics no less than in medicine. If well handled, it can be a great source of knowledge and, maybe, wisdom, necessary for the art of ethics as well as the "good reasons" of ethical justification. There is, moreover, no inconsistency between the affirmation of strong rules and principles and an admission of moral uncertainty.

The medical anthropologist Mary-Jo Good has written most helpfully about the difference and often tension between "cosmopolitan" and "local" medicine.[18] The former medicine is science-oriented, marked by international journals and a common technical language, and makes use of universal standards of human-subject research and acceptable medical evidence. Local medicine, by contrast, will express the medical customs and traditions of a particular society or community, and usually in a way far removed from the austerity and impersonality of cosmopolitan medicine. The point, however, is that both kinds of medicine are valid and needed. Neither should be allowed to obliterate the other, even though they may engage in a permanent argument and jockeying for professional position.

Bioethics could usefully adopt a similar distinction, recognizing the dual need for generality and universality on many occasions and with many problems but acutely sensitive to lived moral lives, to power imbalances, to the special needs of some subcommunities. The latter particularities will offer a running commentary on the reigning principles and moral rules—and purveyors of the latter will listen and be willing to change. I happen to find "principlism" inadequate, but not because it seeks universal principles. They are just not quite the right principles as presently deployed, or, better, not the right principles if used independently of a more communitarian vision, which sees the good of the community as equal in importance to the good of individuals. But we can argue among ourselves about that in bioethics, hoping that the social scientists will put before our eyes what they think they have learned about that ancient tension. Of course, many of us would prefer to have

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that knowledge provided in an organized and general way. Or would we have missed the point if that is the way we want it?

ENDNOTES

[1]Charles E. Lindblom, "Political Science in the 1940s and 1950s," *Dædalus* 126 (1) (1997): 234.

[2]Jessica H. Muller, "Anthropology, Bioethics, and Medicine: A Provocative Trilogy," *Medical Anthropology* 8 (4) (1992): 460.

[3]See Daniel Callahan, "The Hastings Center and the Early Years of Bioethics," *Kennedy Institute of Ethics Journal* 9 (1) (1999): 53–71, for a fuller account of the rise of bioethics, as well as a number of other essays in the same issue that explore the same history.

[4]See, in particular, Tom L. Beauchamp and James F. Childress, *Principles of Biomedical Ethics,* 4th ed. (New York: Oxford University Press, 1997).

[5]The work of the late philosopher Hans Jonas was as much appreciated by a large number of us in the early years of bioethics as it was neglected by the generation of analytically trained philosophers who came after him. The main reason for that respect was that Jonas had good insights and good arguments and had, in his own life, lived through some of the great moral crises of the twentieth century.

[6]See, for instance, Sidney Callahan, *In Good Conscience: Reason and Emotion in Moral Decision Making* (San Francisco: HarperSanFrancisco, 1991), which shows why it has been a mistake for many contemporary moral philosophers to draw too sharp a distinction between reason and emotion.

[7]Alexander Nehamas, "Trends in Recent American Philosophy," *Dædalus* 126 (1) (1997): 219.

[8]Jessica H. Muller and Barbara A. Koenig, "On the Boundary of Life and Death: The Definition of Dying by Medical Residents," in *Biomedicine Examined,* ed. Margaret Lock and Deborah Gordon (Dordrecht: Kluwer, 1988), 369.

[9]Arthur Kleinman, *Writing at the Margin* (Berkeley: University of California Press, 1995), 44–45.

[10]Barry Hoffmaster, "Introduction," in *Bioethics in Context: Social Science Contributions to Moral Understanding,* ed. Barry Hoffmaster (New York: Cambridge University Press, forthcoming).

[11]Barry Hoffmaster, "Can Ethnography Save the Life of Medical Ethics?" *Social Science and Medicine* 35 (1992): 1428.

[12]Thomas Nagel, *The Last Word* (New York: Oxford University Press, 1995), 106.

[13]Joseph Fletcher, *Medicine and Morals* (Boston: Beacon Press, 1954).

[14]Kleinman, *Writing at the Margin*, 55.

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[15]Barry Hoffmaster, "Morality and the Social Sciences," in *Social Science Perspectives on Medical Ethics*, ed. George Weisz (Amsterdam: Kluwer Academic Publishers, 1990), 253–254.

[16]Kleinman, *Writing at the Margin*, 53.

[17]Ibid., 48.

[18]Mary-Jo Good, "Cultural Studies of Biomedicine: An Agenda for Research," *Social Science and Medicine* 41 (4) (1995): 461–473.

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Alexander Morgan Capron

What Contributions Have Social Science and the Law Made to the Development of Policy on Bioethics?

TO WHAT EXTENT has the formation of public policy on bioethical issues been grounded in scientific findings? Very little. Though disturbing, this may hardly seem remarkable: after all, the same is true for most policies, outside of some social-welfare programs that have for a number of peculiar reasons been the subject of "social-policy experiments." But perhaps the absence of evidence of the effectiveness of bioethics policies—either before or after their adoption—is surprising, since the activities in question, biomedical research and practice, are themselves the subject of so much study, and since pragmatism and empiricism are enjoying a revival in the law.[1]

This essay examines one area—decision making at the end of life—where proponents have pushed for policies unconstrained by the lack of social-science research (which is only now occurring), as a means of inquiring why policy-making in bioethics has favored abstract principles rather than empirical findings. Before turning to this central task, however, it seems appropriate to begin by examining three ways in which the law relates to bioethics. First I discuss the law's seminal contributions to the content and analytic methodology of bioethics. Second, I

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argue that bioethics is closely tied not just to clinical practice but to public policy. Third, I examine the particular means whereby the law (typically, legislation or regulation; sometimes, executive or judicial decisions) affects and is affected by bioethical issues.

LAW AND THE CONTENT AND METHODS OF BIOETHICS

Some very grandiose claims have been advanced under the heading of law. For example, George Annas has argued that "American law, not philosophy or medicine, is primarily responsible for the agenda, development, and current state of American bioethics."[2] Since bioethics emerged in the United States in the 1960s, it is true that American institutions and commentators have had a disproportionate influence in shaping the content and methodology of the field, and that that influence has tended to emphasize the law and particular legally based values. Lacking an established church, Americans have the habit of looking to the courts to resolve contentious moral questions, and we expect the courts to implement certain values that are central to our culture, though sometimes inconsistent or at least in tension with it. We are, for example, both meliorist and individualist in outlook (meaning that we believe that people can improve their own futures, especially through the use of initiative and technology) and we are committed to "due process" and formal legal equality (which translates, among other things, into an unwillingness to defer to expert authority).

Implicit in our reliance on the courts is the process of inductive incrementalism, the building up of law in the resolution of individual disputes. While theorists once attempted to paint this as a process of logical development, it is seen now as much messier: the working out of practical accommodations of past decisions and present needs from which some predictions can reliably be made about future outcomes. But these are not the sort of neat derivatives of first principles that would satisfy a logician or comport with the expectations of a lawyer trained in civil law, much less a Platonic philosopher. Of course, law is not the only bioethics-related discipline that utilizes the resolution of cases as a means of developing broad conclusions.

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Christian scholars trained in casuistic reasoning and Jewish scholars adept at Talmudic interpretation rely on similar methods; likewise, the processes used by the courts have much in common with the phenomenological and hermeneutic methods of social scientists and philosophers examining clinical encounters and texts, respectively.

Incrementalism is also fostered by the division of power in the American legal system, both among the branches of government and between the state and federal governments. Rather than favoring sweeping changes, incrementalism encourages less radical ones, capable of finding acceptance among many actors whose hands are on the levers of power. It also encourages experimentation with new policies in "the laboratory of the states," in Justice Brandeis's oft-quoted dictum.

Finally, the roots of bioethics in American law helped drive bioethics toward proceduralism and away from specific normative conclusions. The constitutional separation of religion and public policy was not the only force moving in this direction; it combined with a commitment to a relativistic approach to ethics fed from the 1960s onward in America by the increasingly pluralistic nature of our society. The result is that the bioethics literature is more concerned with who may decide than with the morality of the decision, more often framed in terms of one's right to do something than in terms of what is the right thing to do. Of course, this approach is itself not value-free but reflects a normative commitment to preferring individual choice over other measures of correct action, such as expert judgment, group allegiance, social welfare, or divine command. And its procedurally oriented, facially neutral, and decidedly nonreligious stance owes much to the law's influence on bioethics.

LAW AND BIOETHICS—THE FOCUS ON PUBLIC POLICY

This brief catalog of the contributions of the law—particularly American law—in shaping bioethics should be enough to show that the law has had a pervasive effect on the content and methods of bioethics. Even without going as far as Professor Annas, it is indisputable that the law has been a major shaping

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force in the field's development, along with philosophy, theology, and medicine, and—to a lesser degree—the natural, behavioral, and social sciences. For purposes of the present analysis, however, two points bear particular emphasis.

First, bioethics is not simply a field of philosophy; it is a practical discipline, or, perhaps more accurately if less felicitously, a practical "interdiscipline." Moreover, this practicality lies not simply in its providing guidance for clinical decision making but also in its bestowing rewards and sanctions and resolving disputes. While the latter are often framed as "ethical" disputes, they ultimately become matters for resolution through court or administrative decision, through legislation, or through some combination of these legal methods.

The second point needing emphasis is that bioethics has been driven by famous cases (*Quinlan, Cruzan,* and "Baby M") and crises (the allocation of dialysis machines by the "God Committee" and the transplantation of living hearts from "dead" but breathing bodies; the Tuskeegee syphilis study, the human radiation experiments, and the alarming instances of research on fetuses, prisoners, and the mentally disabled; the moratorium on genetic engineering, leading up to the 1975 Asilomar conference, and the subsequent development of human gene therapies; and the prospect of human cloning, following the announcement of the birth of Dolly, the sheep). Whether arising at the bedside or in the lab, whether brought forward by biomedical scientists and practitioners or by journalists and whistle blowers, and whether explicitly formulated as an issue for official decision or not, issues in bioethics are commonly translated into matters of public policy, both through the resolution of particular disputes and through the promulgation of legislation and regulations.

Plainly, people continue to seek bioethical guidance or insight at a philosophical or moral rather than a legal level as an aid in making decisions about treatment or research, and some people may even explore bioethical topics as a means of purely philosophical discussion about fundamental human questions, such as the meaning of freedom or of personal identity. But bioethics is for the most part concerned directly or indirectly with questions of policy and of permissible behavior of profes-

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sionals, patients, and others, which is to say that it is concerned with the law (meaning not only state regulation and judicial decisions but also the framework within which "private ordering" occurs) and with the rationales on which law rests.

I want to be clear about both the limitations and the ultimate sweep of this claim. On the one hand, my conclusion is modest: I would never claim that the intimate connection between bioethics and public policy means that most participants in bioethics decisions see themselves as making "legal" decisions or taking part in "legal" proceedings. In many—perhaps, in virtually all—routine situations involving a bioethics issue, and probably even in most that are framed by the participants as "cases," the situation never formally becomes a matter for legal adjudication. Indeed, if the participants were asked what guided their decision, other factors—such as "the code of medical ethics," "hospital rules," "local customs," or "the family's preferences"—would be often cited, rather than legal authority.[3] For example, physicians faced with a decision whether to discontinue a respirator or feeding tube for a patient in the persistent vegetative state (PVS) may be guided more by their sense of what their colleagues think is appropriate or by how strongly a family presents its views than by legal precedent in the jurisdiction, and this reliance on internal ethical norms is, I would hazard, actually likely to be greater in those who deal regularly with the issue (such as members of an institutional ethics committee or ICU physicians) than with physicians who only confront the issue sporadically.

There is nothing wrong per se with such a mode of decision making—provided, of course, that the rules of thumb do not deviate *too* far from the actual expectations of the law and that no systematic barriers exist to any of the concerned parties seeking formal legal review of any decision. (The second point plainly reinforces the first; that is, the threat of adjudication, with the accompanying publicity and potential civil, criminal, or administrative remedies, will help to ensure that the rules of thumb do not usually expose the people who follow them to legal sanctions.) Indeed, rather than seeing anything wrong with this, I see reliance on internalized "norms" as an essential feature of a good society. Indeed, in an ideal society, ethical

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behavior would occur without legal coercion: the lamb could lie down unafraid with the lion.[4]

We do not, however, reside in such a heavenly place. In our fallen world laws are necessary, especially for the protection of the less powerful. Thus, as valuable as self-regulation may be, in matters bioethical the law plays an essential role, even though it is not unusual for the law to remain in the background, and indeed for the legal system to be virtually transparent as decisions are made by lay people (not lawyers, judges, legislators, and the like) in a private context. My claim is that even when the decisions appear to rest in private hands, the law is still an important factor, whether providing the *trigger* for decision (e.g., the requirement that federally funded research projects receive prior review by an institutional review board), the *standard* for decision (e.g., the statutes that provide the standards for determining that death has occurred and that authorize next-of-kin to consent to the retrieval from a deceased person of organs for transplantation and other purposes), or the *consequences* of a decision (e.g., the federal regulations about which disciplinary or privileging decisions by a hospital must be reported to the federal data bank on physicians, or the state laws specifying penalties for conducting research on an embryo or fetus).

I realize that my description of bioethics will strike some as very wrong. For them, bioethics is centrally a quest for firmly grounded philosophical principles; without such theoretical foundations, bioethics can make no legitimate claim to affect moral behavior. I would never deny the importance of such an intellectual enterprise, and I recognize that the questions it seeks to illuminate—questions about the nature of human beings, our place in the world, our relationships with one another, and the goals that would allow medicine to promote human flourishing and help create a good society—can challenge our minds and deeply engage our souls. I enjoy the opportunity that bioethics gives to think about such issues, and I value the contributions that bioethicists have made to understanding them. But the process of searching for answers on such foundational issues and of building a theoretical structure is not, I believe, what has made bioethics an important field today: that importance has

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derived from the widespread realization that bioethics affects real decisions about our lives and that it is therefore important for such decisions to be made well. And, as Daniel Callahan has observed, "even if there is no consensus on theory, social, political, and legal agreement of a kind sufficient to allow reasonable moral decisions to be made and policy to be set can be achieved."[5]

THE MEANS WHEREBY THE LAW IMPLEMENTS BIOETHICS AND IS AFFECTED IN RETURN

The characterization I have just provided for the relationship between law and bioethics—namely, that the law has made large contributions to the methodology of bioethics and is the framework within which bioethics-as-public-policy is carried out—could be described as claiming a modest but pervasive role for the law. On the more modest end of the scale, this claim recognizes that most "bioethical decision making" is a matter of private choices that are only occasionally formally reviewed and approved or disapproved. On the pervasive end of the scale, all bioethical decision making takes place in the shadow of the law. When we speak of "the law" in this context, we mean much more than a set of specific criminal or regulatory provisions, more even than civil statutes, judicial decisions, state and federal constitutions, and international treaties and protocols. We also mean the legal systems, the institutions, and the processes through which the law is applied.

Some of the changes wrought in science and medicine by the law have been intentional. To take just one prominent example, the doctrine of informed consent—first articulated by a California appellate court in 1957,[6] elaborated in numerous judicial decisions and statutes, and extensively examined in countless books and articles over the following four decades—has resulted in patients getting much more information about the medical interventions recommended by their physicians than was previously the case. But the effects of changes in the law go far beyond such intentional ones and even beyond those that could have been readily anticipated, such as the increased realization of many patients that the choice among medical

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options (including no treatment) rests in their hands. The doctrine of informed consent—in reality, many different doctrines varying in their particulars by jurisdiction—has not only created a specific legal duty for physicians but also helped to reshape the physician-patient relationship in myriad ways, many of them unanticipated by those who articulated the doctrine. Of course, the effects of the legal doctrine cannot be separated from the effects that were brought about by other forces in society, some of which may have been independent while others fed the legal changes or were fed by them. While, to the best of my knowledge, no study has established whether systematic differences occur in the physician-patient relationship in states with different legal rules,[7] the nature of "informed consent" as a rule governing medical practice is such that differences between jurisdictions are probably less important in shaping physicians' attitudes and behavior than the basic theme that has been pounded home by legal and nonlegal commentators that physicians should engage in a dialogue with their patients before intervening in their lives.

Similar observations could be made about the law as it relates to a host of bioethical issues in *organ transplantation* (such as structuring the transaction as one that rests on individual choice, not social utility, and that depends on voluntary, unpaid donation rather than mandatory takings, at the one extreme, or free-market commercial transactions, at the other), in *reproduction* (such as the framing of the issues as matters of the desires and rights of the adults involved, rather than the welfare of the children produced), in *human subjects research* (in which the paradigm is shifting from a long-standing concern—born of many cases of abuse—to protect human subjects from becoming involuntary victims, to a need both to ensure the rights of persons to access experimental procedures and to avoid victimizing categories of people whose needs are left out of research protocols), and in *genetics* (where tension exists between patent law, which implicitly commodifies the human genome, and privacy and antidiscrimination law, which personalizes the genome and feeds notions of genetic determinism by treating genes as special because of the powerful and integral role they play in defining persons).

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In addition to those areas of the law that have helped define the field of bioethics, many other areas of the law—particularly, the laws governing the manner in which health care is organized and financed—have likewise affected the values and norms that are the concern of bioethics. Take, for instance, the statutes and regulations for federal funding of personal health care through Medicare, Medicaid, and related programs. In addition to their obvious ethical power in determining who gets what kind of care, these programs have shaped the relationship not only between their own beneficiaries and the health-care system but also between the even larger number of patients who pay for their care in other ways (principally through employment-based health insurance) and the health-care system. Moreover, by substituting payment for charity, the programs forever altered the role of physicians and hospitals in society, created what for many professionals were irresistible temptations to depart from traditional ethical standards, and radically altered the economic position of physicians vis-à-vis society and among their different specialties.

It is important to remember that we are speaking of a relationship between a set of activities (roughly, biomedical research and practice) and a social institution (the law), and, as such, the effects flow both ways. It is not as though the law arrives full blown upon the scene and stamps its imprint on the activities in question. Rather, the activities push the law as well. An example will illustrate the point. As of the 1950s, the following syllogism would have been true in the United States: A child born to a married woman is presumed to be the child of her husband until he proves he is not the father by lack of genetic connection; a man who has sexual relations with a woman not his spouse is an adulterer; and a child born from adultery is a bastard. Therefore, if John Doe was born to Mary Doe following her artificial insemination by Dr. Roe using semen from a man other than Mary's husband Tom, then Tom is not John's father; Dr. Roe is probably an adulterer; and John is a bastard (and perhaps the illegitimate son of the semen donor). Such was indeed the holding of at least one court in the early years of artificial insemination by donor (AID). Today, as a result both of judicial decisions and of statutes, John Doe

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would be regarded as the legitimate issue of Tom and Mary Doe's marriage, provided that the insemination was carried out with Tom's consent by a licensed physician (who, incidentally, would not be regarded as an adulterer). These legal changes respond both to the underlying technical developments in medical practice and to the social consensus that it is legitimate for couples to go outside of their marriage to obtain assistance from physicians and from gamete donors (in reality, vendors, not donors, when payment is made) and that a child born in such a fashion should not be burdened either by social stigma or by the medical complications that arose when physicians (reacting to the old version of the law) tried to disguise the fact of AID and even destroyed records about the donor, thereby rendering unavailable potentially important medical information.

The court reports, statute books, and regulatory codes are by now replete with thousands of instances in which biomedical developments have reshaped the law. These effects are not limited to specific adoptions of new rules by courts, legislatures, and other law-giving bodies. For example, the clash between the legal strictures of the state of Connecticut forbidding the use of contraceptives and the ethical decisions of physicians who thought contraceptives were necessary to meet the medical needs of their clients led the Supreme Court to articulate a constitutional "right of privacy."[8] Therefore, someone describing the United States Constitution in 1965 would be working from a document different from the one of 1964.

Throughout the law, then, the acceptance or rejection of biomedical practices by law-giving bodies (including, but not limited to, the courts as interpreters of the common law, statutes and regulations, and state and federal constitutions) reshapes the law, sometimes by explicit changes in the law, sometimes by tacit acceptance.[9] How this phenomenon of law-making should be appraised is itself a matter of jurisprudential debate, but most commentators would agree that the law that arises from judicial decision, like that which arises from legislative enactment, embodies normative choices through a process that (with greater or lesser explicitness and self-consciousness on the part of the judiciary) involves determining the

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existing state of the law, weighing competing ends and interests, and pronouncing new rules and practices in light both of existing rules and of an evaluation of which rules and practices are most likely to achieve the preferred ends and interests while causing the least harm to other interests.

A CASE STUDY: POLICIES ON DECISION MAKING AT THE END OF LIFE

The focus of our concern, then, is on the extent to which the adoption of policies on bioethics relies on social-science findings, specifically in anticipating the beneficial and detrimental aspects of such policies. As suggested above, bioethical issues have become matters for policy-making across a wide range of health-care practices. I propose to take a closer look at the role social science has played regarding policies for decisions at the end of life, because this is the arena in which bioethical issues touch the lives of more people than any other, and because it is probably the arena that has produced the largest number of important judicial decisions and statutes.

A century ago, Oliver Wendell Holmes, Jr., proclaimed that the future of the rational study of law belonged not to "the black-letter man" but to "the man of statistics and the master of economics" and lamented the reliance on the "blind guess" to explain existing public policies.[10] While practitioners like Louis D. Brandeis and academics such as Roscoe Pound argued with some success that courts and legislatures should take into account studies of the actual effects of legal institutions, doctrines, and statutes, the legal system overall has remained little affected by Holmes's observation that the life of the law has been not logic but experience. Even with the fading of the Progressive faith that activated the sociological jurisprudence of the early decades of this century and its replacement by the more cynical and psychologically oriented "Realist" movement in the 1930s, empirical study of the law has remained a minor activity. In the nearly seventy years since Karl Llewellyn boldly announced the Realist conception of law "as a means to social ends and not as an end in itself; so that any part needs constantly to be examined for its purpose, and for its effect, and to

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be judged in light of both and of their relation to each other," few have taken up his challenge for "sustained and programmatic" study.[11]

Thus, it should come as no surprise that the brief review of policy-making about end-of-life decisions that follows will demonstrate that they have largely been adopted without much empirical reason to believe they could achieve the goals their authors proclaimed. The review may be of interest nonetheless, as it illustrates just how strong the drive toward certain policies can be despite the absence of data or even in the face of data that demonstrate their problematic consequences. The review will consider three policy areas in turn: the forgoing of life-support, the use of advance directives for health-care decisions, and the struggle over legalization of physician-assisted suicide and euthanasia.

Forgoing Life-Sustaining Treatment

The double-edged nature of the magnificent technological sword wielded by medicine today is nowhere more apparent than in the remarkable techniques available to forestall death. Since the 1960s, these techniques—from drugs to cardiopulmonary resuscitation (CPR), from methods of delivering food and fluids to unconscious patients to the congeries of machines and personnel that constitute the intensive care unit (ICU)—have enabled physicians and other health-care professionals to save the lives of countless acutely ill patients. Yet not infrequently the application of these techniques is sufficient to maintain or restore bodily functions but leaves the patient permanently damaged in mind and body. By the early 1970s, the plight of such patients had produced calls for a reexamination of the medical custom of routinely employing every possible method of extending life. In urging more selective use of life-sustaining technology, some commentators objected that current practices wasted scarce resources, others sought changes in the care of the dying to ensure "death with dignity," while still others argued that decisions about when to use and when to forgo life-prolonging interventions should be left to patients or their next-of-kin or other surrogates.

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The subject moved out of hospital conference rooms and bioethics journals and onto the front pages in 1976 when the New Jersey Supreme Court decided the *Quinlan* case, in which the father of a young woman who had slipped into a coma after ingesting an unknown combination of alcohol and drugs sought to be appointed her guardian for the purpose of instructing her physicians to disconnect the respirator that they believed was necessary to keep her alive. The physicians had refused, saying both that doing so was inconsistent with medical standards of practice and their ethical obligations to their patients and that it would violate the state's prohibitions on homicide and assisting suicide. The court granted Mr. Quinlan's petition and ruled that if his decision were supported by a "hospital ethics committee" neither the civil nor the criminal law would present any barriers to carrying it out. In examining the reasonableness of the father's decision, the court imagined what Karen Quinlan would say were she miraculously (albeit briefly) restored to consciousness, and the justices had no difficulty in concluding that she would not wish to continue indefinitely in her unconscious state. In the following years, both the New Jersey courts and those in other jurisdictions ruled in dozens of similar cases and, with small differences in the standards applied from state to state, largely reached the conclusion that both competent patients and those who spoke on behalf of incompetent patients could order that life-sustaining techniques be withheld or withdrawn. Although the Supreme Court declined for more than a decade to review these state court rulings on forgoing life-support, it finally accepted a case from Missouri and in 1990 handed down *Cruzan* vs. *Director, Mo. Dep't of Health*.[12] In the course of ruling that the U.S. Constitution did not preclude states from limiting the forgoing of life-support to cases in which there was "clear and convincing evidence" that this was the patient's wish, the justices explicitly assumed that competent patients have a right to refuse any treatment, even when doing so will lead to their deaths.

Several points stand out in this twenty-year history of judicial support for the right to refuse life-sustaining treatment. The first is that from the outset the issue was framed as a question of legal—and, in particular, constitutional—rights.

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While the New Jersey court could have decided the case under widely accepted common law precepts (in sum, that a patient's informed consent is a necessary predicate for any medical intervention), it instead accepted the framework presented by the Quinlans' attorney, who had framed their case in terms of the constitutional "right of privacy" that the U.S. Supreme Court had applied several years earlier in the context of recognizing a woman's right to obtain a therapeutic abortion. Constitutional analysis is almost by definition more abstract than the common law, which grows out of the resolution of rich, contextualized disputes. Thus, from the outset, judicial analysis of forgoing treatment was framed in grand terms, a clash of basic principles that drew on the principlist tradition in bioethics—in which, not surprisingly, the principle of self-determination trumped other concerns.

Second, the court made certain assumptions about the views of the "average, reasonable person," which is the reference point for one of the two standards (namely, "best interests") applied in the case of patients who cannot speak for themselves, which is relied upon when a patient's wishes regarding life-support are not known to the decision maker. When the patient's preferences regarding life-support can be inferred from earlier statements, the alternative standard ("substituted judgment") is employed. Yet the members of the New Jersey Supreme Court gave no indication of the evidence on which they were relying, and, other than their own sense of what they (or perhaps their family and friends, assuming the justices had inquired) would want under the circumstances, it is hard to imagine what basis they had for declaring when it was appropriate to forgo treatment. (Had they chosen to address only the legitimacy of allowing a father to make this decision for his comatose daughter, they could have avoided having to establish any collective standard on this matter.)

Perhaps the most remarkable feature of the decision was the court's ruling that the surrogate's decision should be honored if a hospital ethics committee concurred with the prognosis that Karen Quinlan would never return to a "cognitive, sapient state." While it may seem odd to rely on an "ethics" committee to confirm a medical prediction, that particular aspect of the

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case has been explained as the justices' desire to make sure that the representation of Ms. Quinlan's medical condition as it appeared in the trial record was still accurate, and their sense that they themselves had resolved the more "ethical" issue of whether it was licit to discontinue the respiration if Ms. Quinlan's condition was confirmed to be "hopeless." Therefore, putting aside the specific issue the court handed the ethics committee, what is most remarkable is the court's apparent assumption that ethics committees were a well-established feature of the hospital landscape in 1976. The source of (one might as well say the inspiration for) the idea of reliance on a hospital ethics committee was a very short article in a law review derived from a talk by pediatrician Karen Teel.[13] Dr. Teel herself offered no details about the decision-making methods of or standards for such committees and nothing but the sketchiest description of a committee's makeup and the like. Thus, neither she nor the court was able to cite any empirical evidence that such committees could function effectively, much less that their use would improve the quality of clinical decision making for patients on life support. Today, virtually all acute-care hospitals (as well as many long-term and other facilities) have ethics committees; while the prevalence of such committees owes more to developments in the 1980s (such as the so-called Baby Doe regulations and the adoption by the Joint Commission on Accreditation of Healthcare Organizations of the requirement that accredited organizations have some means of providing ethical evaluation and advice in difficult cases) than to the *Quinlan* decision directly, the general adoption of this particular method of addressing bioethics issues at the local level is little better validated by empirical evidence today than when it was first imposed by the New Jersey Supreme Court more than twenty years ago.

Legislating Advance Directives

Beginning with California, which acted within months of the New Jersey decision, states across the country responded to the plight of patients like Karen Quinlan who had lost the capacity to participate in decisions about life-sustaining treatment by adopting so-called Living Will or Natural Death statutes that

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permitted people to issue instructions in an "advance directive" that they would not want their lives prolonged if they were "terminal" and could not express their wishes contemporaneously. Then, in 1983, the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research suggested in one of its reports that such "instruction directives" ought to be supplemented (or even replaced) by "appointment directives" in which a person while competent would name the surrogate(s) who would be authorized to step into the person's shoes and make treatment decisions in the event the person became unable to do so for him or herself.[14] Specifically, the President's Commission recommended that the concept of Durable Powers of Attorney, which had recently been legislated in many states as a means for people to appoint someone to manage their affairs when they became incompetent, be extended by legislating the Durable Power of Attorney for Health Care, which would specifically address concerns that arise in giving one person the authority to direct the termination of life-support of another person who has not directly instructed when and how such steps should be taken.

While the President's Commission recited the rationale that lay behind the adoption of durable power of attorney laws and the reasons to believe that they would offer a valuable supplement or alternative for living wills, there were no studies on which it could draw to establish that such means would prove useful to patients or would affect the behavior of health-care professionals and institutions. Over the past fifteen years virtually every state has enacted some form of advance directive statute, authorizing use of instruction or appointment directives or both, culminating in the federal government requiring in the Patient Self-Determination Act (PSDA) that hospitals and other health-care providers inform patients of their rights to make end-of-life decisions and specifically to execute an advance directive. Yet most of the evidence that has accumulated suggests that few patients use advance directives effectively and that in the eyes of the attending medical personnel the wishes of dying patients regarding life support are regarded as opaque or even irrelevant.

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Another concern about advance directives centers on whether they are to be faulted for embodying an extreme view of the role of individual self-determination. This concept, often framed in philosophical discussions as the principle of personal autonomy, has received a great deal of support from the law, especially in its negative form—that is, a person's right to be left alone, free of interference by the state or by benevolent professionals aiming to protect the person from his or her own bad judgment or mistaken beliefs. Advance directives are extreme in that they are designed to allow individuals to control not only what can be done to their persons now but also what will be allowed at a future time when they are unable to participate in decisions. Further, in a subtle way, the fact that wishes are written down (by a person who is later unable to participate in a discussion about what would be best under the circumstances) can carry the right from the purely negative ("do not do that to me") to the positive ("I demand to have this or that").

Advance directives have therefore been criticized both for creating problems for the people who really have to make decisions by robbing them of necessary flexibility and for handing authority regarding an incompetent patient's health care over to a "stranger"—namely, the person who filled out the advance directive, who is a *different person* from the present patient.

While this criticism proceeds at a philosophical level, a series of social-science questions can be asked to similar effect regarding advance directives. For example, an interdisciplinary team of physicians, social and behavioral scientists, lawyers, and bioethicists at our health policy and ethics center at the University of Southern California recently conducted a two-year study of the effects of ethnicity on attitudes toward care at the end of life and particularly toward advance directives. In the first year, a stratified quota sample of two hundred subjects aged sixty-five years and older from each of four ethnic groups (African-American, Korean-American, Mexican-American, and European-American) were recruited through thirty-one senior-citizen centers within Los Angeles county. These subjects went through a one-hour questionnaire interview conducted by per-

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sons of their own ethnic background. Regression analysis of the data showed that ethnicity was the most significant factor accounting for differences in the attitudes of the four groups toward being truthful with patients about their diagnosis and prognosis and patients' control of decisions about their medical care, particularly at the end of life.[15]

A persistent issue regarding advance directives has been why the positive attitudes toward these documents is accompanied by relatively low completion rates. Is it simply a matter of ignorance or lack of access, both of which should be overcome by the PSDA? Or might the problem be that the studies relied upon by advocates of advance directive legislation involve predominantly white middle-class respondents? For example, in one oft-cited study, Linda Emanuel and her colleagues excluded individuals with a "language barrier," resulting in a sample in which 25 percent of the respondents possessed a postgraduate level of education.[16] Our center's study confirmed suggestions from earlier research that more diverse samples produced not only less knowledge about advance directives and fewer completions of them but also less favorable attitudes toward advance directives, particularly among the Mexican-American and Korean-American respondents. The findings suggest that "the process of end-of-life decision making is more complex than previously imagined. The concept of advance care documents may appeal only to certain subsets of the population, limiting the clinical usefulness of living wills and durable powers of attorney for health care."[17]

The risk that public policy could force clinical encounters into patterns that are alien and unproductive—indeed, perhaps even destructive—for some patients was further substantiated during the second year of the study, during which twenty respondents from each of the four groups were reinterviewed in a two-hour, structured, open-ended, ethnographic format. This study confirmed the view that not all patients expect or want full disclosure of their diagnosis or prognosis even though bioethics has generally embraced the patient-autonomy model and emphasized the importance of truth-telling. Not all patients deal with the causes and nature of their illnesses primarily in biomedical terms, nor do they all understand and accept that

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American physicians increasingly expect patients to decide between treatment options. "If bioethics policies are to meet the needs of patients whose values are different than those of the dominant white middle class, more must be known about the diverse clinical situations in which life-and-death decisions are made."[18]

Analyzing an interview with a typical Korean-American respondent (a seventy-nine-year-old pseudonymously named Mrs. Kim), the researchers showed how a patient who would not want her life prolonged by medical treatment if she were terminally ill with cancer nevertheless would expect that decisions about her care would be made by her children, who would demonstrate their filial devotion by insisting on all care that could prolong her life. As Mrs. Kim states, "If my children wanted to see me even one more day, then they might ask for the treatment; I am the one who is going to die, so I don't control the situation."[19] Clearly, Mrs. Kim rejects the individual autonomy model assumed by the law; later in the interview, she makes clear that it is not good for patients to sign advance directives because a person cannot know his or her fate or future, and she expects her family to make a decision for her, whether or not she signs an advance care document. Furthermore, the interview reveals that the expectation inherent in the use of advance directives—namely, that a physician will talk with a patient about the latter's impending death—does not comport with her culture, in which such information is given to family members but withheld from the patient.

Legal Acceptance of Physician-Assisted Suicide and Euthanasia

No other aspect of decision making at the end of life—and virtually no other topic in bioethics as a whole—excites more vigorous disagreement today than physician-assisted suicide and euthanasia. Moreover, this topic also illustrates the way in which bioethics discussions focus on the policy question (is it legal?) in place of the ethical (when, if ever, is it right?). In the public debates, the issue is the legalization of physicians' assistance of their patients in this fashion, rather than the messier existential, spiritual, psychological, sociocultural, and even

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medical and pharmacological aspects that actually arise when a request for assistance is made.

Advocates of legalization typically portray it as simply the natural extension of the already recognized right to forgo life-sustaining treatment. In this they are simply standing on its head the argument made by some prosecutors and physicians in the 1970s and early 1980s that a treatment termination that would probably result in a patient's death amounted to homicide (or assisted suicide, if undertaken at the patient's request). Current advocates for physician assistance contend that the courts that rejected such claims were wrong to decide that forgoing life support did not amount to killing patients yet were correct in holding that forgoing life support under these circumstances was not *wrongful* killing. Thus, by analogy, it should not amount to a wrongful killing for physicians to bring about death by active means, just as they are allowed to do through so-called passive means.

The arguments in favor of decriminalizing physician assistance in bringing about death have been presented in the form of proposed statutes (in state legislatures and through public referenda) and of court challenges to existing prohibitions on assisting suicide. The movement has been unsuccessful in the legislatures; indeed, a number of states have adopted or clarified laws forbidding acts aimed at causing patients' deaths, while at the same time making it legal to use medication to relieve pain even when doing so has the foreseeable though not intended consequence of accelerating the dying process. While the first two ballot measures to legalize physician-performed euthanasia (in Washington state in 1990 and in California in 1992) failed by narrow margins, a narrower statute—which authorizes physicians to prescribe lethal medication for competent, terminally ill adults who request it, but which removes the physician from the role of actively engaging in mercy killing—was approved by 51 percent of Oregon voters in 1994 and reaffirmed by a wider margin in a second vote in November of 1997.

The focus on judicial review of assisted suicide prohibitions came in two cases in which federal appellate courts in 1996 struck down state statutes as unconstitutional under two differ-

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ent clauses of the Fourteenth Amendment, only to have their decisions reversed by the United States Supreme Court. In *Washington* vs. *Glucksberg,* the U.S. Court of Appeals for the Ninth Circuit invalidated Washington state's prohibition on assisting suicide as it applied to physicians helping competent, terminally ill adults who request the physicians' assistance in ending their lives.[20] Drawing on broad concepts of personal self-definition invoked by the Supreme Court in upholding the right of women to obtain an abortion, the Ninth Circuit en banc panel held that dying patients have a liberty interest, which is protected against state interference, in deciding "the time and manner of their death" under the Due Process Clause of the Fourteenth Amendment. While the Ninth Circuit had no need to rule on the plaintiffs' claim that the Washington statute also violated the Equal Protection Clause, the latter claim was the basis for a ruling by the Second Circuit, which rejected the due process argument but found New York State's assisted suicide law unconstitutional on equal protection grounds as applied to prevent physicians from aiding competent, terminally ill patients to die.[21] The appellate court reasoned that a state could not rationally permit some patients to obtain physicians' aid in ending their lives by forgoing life-sustaining treatment while prohibiting other patients from obtaining physicians' aid in ending their lives (through a prescription for lethal medication) simply because they were not dependent on life support.

The Supreme Court reversed both appellate courts. In the Washington case, it declined to promulgate a new liberty interest not specified in the Due Process Clause, since such an interest in having assistance to end one's own life finds no warrant in our legal or social traditions and is not an essential feature of a system of "ordered liberty." In the New York case, the Court had no difficulty in distinguishing between the two categories of patients and hence in concluding that equal protection was not violated by treating them differently. In each case, the Court concluded that the state had adequate rational grounds for forbidding anyone from aiding another to commit suicide.

What is notable about the judicial resolution of this issue is that the appellate courts found a constitutionally protected

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right to assisted suicide by relying mostly on abstract rhetoric: "the Second Circuit ignored the factual issues," while the Ninth Circuit "attended to some empirical data . . . but then based much of their reasoning on assumptions without factual underpinning," as Susan Wolf has recently written.[22] While the respondents followed the same tack in the Supreme Court, Professor Wolf argues that the Justices took a different approach and "struggled openly with questions of empiricism. It was a problem they never solved; as in prior cases, the Justices remained vexed by the role of data," with Justices Souter and Stevens explicitly addressing the gaps. Wolf concludes: "Even among the other Justices, concern about clinical realities moved them away from acontextual rhetoric. For many of the Justices, the facts or sheer factual uncertainty drove them to send the assisted suicide question back to the legislatures."[23]

It remains to be seen whether the public debates on this issue will move beyond rhetoric about rights and the presentation of assisted suicide in idealized terms and will instead place the debate "in the context of data, tethering claims to the realities of the clinic."[24]

WHY ARE BIOETHICS POLICIES NOT EMPIRICALLY GROUNDED?

As this selective examination of one major area of bioethics indicates, much formation of public policy on bioethics is undertaken with little or no reliance on evidence that the policies adopted will achieve their proclaimed ends, much less that these ends coincide with the interests of the people affected. While this is not unique to bioethics, the widespread tendency of legislators and judges to make laws in the absence of empirical support for the policies they are adopting or the practices they are endorsing (or forbidding) seems to be worse in this field. Several explanations for this phenomenon deserve consideration; the first three have their origins in the law-making processes themselves, while the last focuses on social science.

The Constitutionalization of Bioethics

It is typical, when bioethics moves into the policy arena, for the claims of the competing parties to be framed in terms of rights.

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Sometimes these rights seem to be drawn from natural law or from broadly stated international covenants, but in American courts and legislatures the rights are usually framed in constitutional terms. We have just seen how this has been true regarding end-of-life issues from *Quinlan* onwards. Likewise, research with human subjects pits individual self-determination against scientists' right of free inquiry, and the use of assisted reproduction is framed in terms of reproductive liberty versus the state's power to protect the vulnerable (namely, the products of the new reproductive methods).

Policy-making that is abstracted to the level of major principles (a tendency in line with much bioethics writing itself) offers few openings for social-science data. First, the energy of the combatants is focused on questions of rights and fundamental interests, a rhetorical enterprise that diverts them from attending to factual concerns. Second, it is not clear where data, other than historical studies that might illuminate whether the right in question has any direct or indirect historical analogues, would play a role. It is almost irrelevant whether a particular right is likely to produce good or bad consequences: the right to a fair trial allows some wrongdoers to go free, the right to free speech allows all manner of false and misleading information to be disseminated, and so on. How is it relevant, then, to deciding whether the due-process clause protects a right to assistance in committing suicide, that studies of active euthanasia in the Netherlands show that many cases are not reported as required and even that the practice has expanded beyond voluntary euthanasia of competent adults with unrelieved suffering from a terminal condition to include some patients who never gave consent, much less requested, that their lives be ended, some who are children, and some who are in the early stages of their disease or whose affliction is not lethal? Likewise, what difference would it make if study after study were to show that physicians are very poor at accurately prognosticating when a patient will die, which would not only call into question their ability to determine reliably that a patient is "terminal" (in terms of a six-month prognosis, as specified in the Oregon statute) but also make it likely that some patients would make decisions about when to end their

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lives on the basis of erroneous information? If the constitution prevents a state from flatly prohibiting dying patients from exercising their right to a physician's aid in bringing about death, then these data (even if undisputed) would be irrelevant to the declaration of a "right," though they might provide reasons for individuals or the state to adopt certain procedures to minimize errors or to police the behavior of physicians and pharmacists with particular care.

It seems to me that there is a certain irony in the acontextual nature of constitutional adjudication. Constitutional law occupies a rather exalted (and, as we have seen, rarefied) position in the *corpus juris*. Yet the legal process, which in garden variety cases is so attentive to the finest details about individuals and what they have done, seems so cavalier about social facts and empirical findings in resolving major policy disputes in which the particular details of the parties who have brought the case are typically of little import (beyond framing a "story" to explain why the issue has arisen) precisely because the issues have been abstracted to a very high degree as matters of conflicting principles, framed as state interests and individual rights.

In sum, when bioethical dilemmas are translated into a clash at the level of principles and constitutional rights, the focus shifts away from careful attention to nuances of human behavior and organizational arrangements and away from data on how various policies affect behavior and outcomes. Instead, the arguments are framed in terms of precedent and of the implications of one outcome or another, not at the clinical level but in terms of the effect on legal doctrine itself. In the *Vacco* decision, for example, the Court attempted to rest the differences between forgoing life-support and obtaining assistance in committing suicide on the doctrines of causation and intent, and, further, it wanted to be sure that in recognizing the state's authority to prevent a person from acting to cause death by lethal medication it did not undermine the authority of patients on life-support to decide with their physicians—free of state interference—to withdraw the medical interventions that were keeping them alive. While the development of legal doctrine is, of course, an important task for lawyers and judges, concen-

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trating on this alone misses much that is crucial to the development of defensible policies. As Jessica Muller recently remarked,

> It is critical to examine how people actually behave in problematic situations and the reasons or justifications they give for their behavior. The application of abstract rules or principles often is not sufficient to grasp the complexities or subtleties of real life situations of moral conflict.[25]

The Role of the Political Process

Legislation about bioethical matters offers greater scope for social-science data than does judicial resolution of constitutional claims, and such data have sometimes been employed in debates about bioethics policies. Yet like constitutional arguments (which are also legitimate features of legislative decision making), legislative discussions of bioethical issues can be swamped by ideology. Indeed, many topics in bioethics touch on highly charged issues (such as the right to life, sexuality, and control over one's body) with the result that policy positions are often hotly contested. Moreover, whether resolved in the statehouse or at the ballot box, debates about statutes take place within a political process. Even when not so polarized along ideological lines that it is beyond the influence of social science, politics is the art of the possible, not the science of proven results. In reaching accommodation between competing forces, politicians have to be willing to compromise, a process that is usually made more complicated by too keen an insistence on the rigor of logic or the niceties of data. Moreover, whether compromise or pitched battle is the outcome, politicians often find it advantageous to mount rhetorical appeals to their constituencies; again, such appeals are most likely to succeed when not encumbered by any but the starkest and most basic facts about the issue in question, so that studies that bring out the complexities and uncertainties that characterize most problems in bioethics are not likely to be utilized.

Uncertainties over "Legislative Facts"

Part of the difficulty in wedding social science to the normative process of law-making arises from the disputed nature of what

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Kenneth Culp Davis called "legislative facts"—a term he invoked to distinguish them from "adjudicative facts," the findings of fact about a specific set of circumstances and actions that relate to the specific case under decision. As an expert on administrative law, Davis was originally concerned with the decisions made by agencies in which statutes and regulations are crafted and applied to individual cases, but his development of the role of legislative facts is relevant not only to the legislative process, in which lawmakers utilize statutory "findings" as well as committee reports and floor debate to specify the facts that lie behind enactments, but also to the adjudicative process, in which courts sometimes rely on data beyond that which has been formally introduced through testimony and exhibits at trial.[26] Relying on such data—which has not had to meet the requirements of the rules of evidence nor be tested in the crucible of cross-examination—can be controversial, whether it amounts to courts taking "judicial notice" of certain supposedly undisputed facts (which usually relates more to specific facts in the "adjudicative" rather than "legislative" category) or to the looser and less well-defined practice of courts (usually at an appellate level) using social and economic data that are recited in briefs (of the parties or of amicus curiae) or even developed through a judge's own research in the literature. These practices—widely associated with Justice Brandeis, who made them famous with his submission to the Supreme Court in the 1907 case *Muller* vs. *Oregon*,[27] and who continued citing social and economic studies after being appointed to the Court—arise particularly in constitutional adjudication, although they also come into other cases.

People concerned with the absence of empirical data in the formation of public policy about bioethics might be expected to encourage more use of legislative facts by courts in their lawmaking. But bioethicists are also sensitive to the difficulty of separating facts and values, especially when data are analyzed by judges who are likely to be untutored in the fields on which they are pronouncing and hence unsophisticated in the manner in which they must collect and evaluate "the facts." Values shape not only the way data are presented but also the ways in which researchers frame their questions or hypotheses, the data

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they regard as relevant in answering questions and testing hypotheses, and the standards (such as the statistical formulae) on which they rely to pronounce questions answered or hypotheses proven. Even the Supreme Court's recent *Daubert* decision, revising the standards for admitting scientific evidence in federal trials, while widely praised for taking better account of scientific methodology than the *Frye* test that it replaced, seems very unsophisticated in its understanding of the role that (often unrecognized) values play in scientific investigation.[28]

Likewise, the experience of courts in deciding end-of-life cases raises a red flag about some of the "facts" that courts may pluck from various sources without affording the parties the chance to explore the matter through cross-examination and the like. Think, for example, about the New Jersey Supreme Court's apparent assumption that hospital ethics committees were a familiar part of the landscape at the time of the *Quinlan* decision, whereas in fact they were a largely unknown and untested innovation and are even now inadequately studied.

Thus, while judicial (as well as legislative) reliance on social-science data is probably preferable to the alternative—namely, policy formation based solely on lawmakers' personal knowledge, prejudices, and ideologies, perhaps going directly against existing data—it is still fraught with difficulty. Indeed, as Justice Souter recognized in his concurring opinion in *Glucksberg*, courts should be reluctant to reach conclusions based on such data when the interpretation of the data is subject to such vigorous dispute, like the various findings about the Dutch experience with "legalized" euthanasia. When the risks in question involve irreversible harm to vulnerable populations (e.g., euthanasia of very sick patients who might not be acting voluntarily), Justice Souter's conclusion in *Glucksberg* that courts ought to wait until evidence of safety is firmer seems appropriate, as disappointing as it may be to those who share his sense that the state should be held to high standards of proof when acting to limit their citizens' decisions about their own lives.

The Absence of Relevant Evidence

Having identified the manifest failures of policymakers to avail themselves of empirical evidence in crafting and evaluating

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laws that relate to bioethics, I think it is reasonable to inquire what would happen if tomorrow they heeded my message and reformed their processes. Would they find more than a relatively few studies that would provide much guidance? Setting aside the many reports that deal with the experiences of a single institution (such as a hospital, group practice, or medical school) and small-scale "laboratory" experiments (such as those ascertaining the attitudes of groups of patients about different forms of communication in the informed consent process), even the most widely cited studies that provide broadly generalizable data have more to say about clinicians' behavior and about the effectiveness of various types of medical interventions in producing particular results than they do about public policies themselves. And even the studies that directly raise questions about the effectiveness and appropriateness of particular public policies (such as the study of ethnicity and attitudes toward advance health-care directives) do a better job of showing weaknesses than they do of providing evidence for alternatives that work better. More interdisciplinary collaboration between social and behavioral scientists, lawyers, philosophers, and clinicians will be needed—along with greater receptivity and tangible support from policymakers—if the social sciences are to help the law foster better outcomes for bioethical dilemmas.

ENDNOTES

[1]See, e.g., Michael Brint and William Weaver, eds., *Pragmatism in Law and Society* (Boulder: Westview Press, 1991); Steven D. Smith, "The Pursuit of Pragmatism," *Yale Law Journal* 100 (1990): 409; Susan M. Wolf, "Shifting Paradigms in Bioethics and Health Law: The Rise of a New Pragmatism," *American Journal of Law and Medicine* 20 (1994): 396.

[2]George Annas, *Standard of Care: The Law of American Bioethics* (New York: Oxford University Press, 1993), 3.

[3]Of course, this phenomenon is not unique to bioethics but arises in many arenas that would seem to be more "legal" on their face. For example, insurance adjusters apparently apply rules of thumb (under which some tort liability rules are relaxed) in sorting out the myriad claims that arise from automobile accidents involving their policyholders. This simplifies the process of deciding the extent to which each company will pay for the losses suffered by its own policyholders and by other victims of the accident who are insured by other

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carriers; the rules of thumb result in "trade-offs" among the companies that on balance allocate funds fairly enough to all over time to counterbalance any lost precision in not using the stricter tort rules to allocate losses in particular cases. See H. Laurance Ross, *Settled Out of Court: The Social Process of Insurance Claim Adjustment* (Chicago: Aldine Publishing, Co., 1970).

[4]Cf. Grant Gilmore, "The Storrs Lectures: The Age of Anxiety," *Yale Law Journal* 84 (1975): 1022, 1044. "A reasonably just society will reflect its values in a reasonably just law. The better the society, the less law there will be. In Heaven there will be no law and the lion will lie down with the lamb."

[5]Daniel Callahan, "Bioethics," in Warren Thomas Reich, ed., *Encyclopedia of Bioethics,* rev. ed. (New York and London: Simon and Schuster, 1995), 247, 253. Callahan describes this as the position "at the other extreme" from the view that bioethics must be grounded in agreed-upon theory.

[6]*Salgo* vs. *Leland Stanford, Etc. Bd. Trustees,* 154 Cal. App.2d 560 (1957).

[7]For example, none of the 377 articles in "Empirical Research on Informed Consent: An Annotated Bibliography," *Hastings Center Report* 29 (January-February 1999, Special Supplement): S1-S42, addresses this topic. The compilers of the bibliography, in answer to a reader's doubts about the point of all the empirical research, drew an analogy to the rigorous testing required for other interventions in clinical care and research: "As the history of medicine makes clear, adopting interventions without evaluation might inadvertently expose large numbers of patients and research subjects to inadequate methods of obtaining consent." Jeremy Sugarman et al., "Why Study Informed Consent?" *Hastings Center Report* 29 (July-August 1999): 4 (authors' reply to letter to the editor).

[8]*Griswold* vs. *Connecticut*, 381 US 479 (1965).

[9]The content of "the law" extends beyond positive declarations to encompass practices that are permitted. For example, until very recently there were no statutes or judicial decisions that established the right of the next-of-kin of an incompetent adult to make medical decisions on the latter's behalf; however, in cases in which physicians had obtained the next-of-kin's permission for a medical procedure but in which reliance on the next-of-kin was not contested, judges not infrequently simply noted the consent without comment, so that a lawyer could feel reasonably secure in predicting that a physician-client following the widespread medical custom of obtaining consent in this fashion was acting "within the law."

[10]Oliver Wendell Holmes, Jr., "The Path of the Law," *Harvard Law Review* 10 (1897): 457, 469–470.

[11]Karl N. Llewellyn, "Some Realism about Realism—Responding to Dean Pound," *Harvard Law Review* 44 (1931): 1222.

[12]*Cruzan* vs. *Director, Mo. Dep't of Health*, 497 US 261 (1990).

[13]Karen Teel, "The Physician's Dilemma: A Doctor's View: What the Law Should Be," *Baylor Law Review* 27 (1975): 6.

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[14]President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, *Deciding to Forego Life-Sustaining Treatment* (Washington, D.C.: President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, 1983). Professor Sandra H. Johnson contrasts this report with SUPPORT (The Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment), "the most extensive empirical examination of bioethics 'at the bedside' to date," a study of 9,105 critically ill, dying patients conducted from 1989 to 1994 and funded by the Robert Wood Johnson Foundation:

> The President's Commission produced a document that provided the foundation for the development of the law and principles of bioethics regarding life-sustaining treatment decision. This document, *Deciding to Forego Life-Sustaining Treatment,* has been cited in no fewer than thirty-five appellate judicial opinions resolving end-of-life treatment issues. In the nearly twenty years that passed between the President's Commission and SUPPORT, the basic principles of bioethics, especially as they were captured in law, remained grounded primarily in the "head work" of the Commission and its progeny.

Sandra H. Johnson, "End-of-Life Decision Making: What We Don't Know, We Make Up; What We Do Know, We Ignore," *Indiana Law Review* 31 (1998): 13, 17–18.

[15]Leslie J. Blackhall et al., "Ethnicity and Attitudes Toward Patient Autonomy," *Journal of the American Medical Association* 274 (1995): 820.

[16]Linda L. Emanuel et al., "Advance Directives for Medical Care—A Case for Greater Use," *New England Journal of Medicine* 324 (1991): 889.

[17]Sheila T. Murphy et al., "Ethnicity and Advance Care Directives," *Journal of Law, Medicine, and Ethics* 24 (1996): 108, 116.

[18]Gelya Frank et al., "Attitudes Toward Patient Autonomy Among Elderly Korean-Americans," *Medical Anthropology Quarterly* 12 (1998): 403, 405 (citation omitted).

[19]Ibid., 411.

[20]*Compassion in Dying* vs. *Washington,* 850 F. Supp. 1454 (W.D. Wash. 1994), rev. 49 F3d 586 (9th Cir 1995), aff'd. 79 F3d 790 (9th Cir 1996) (en banc), rev. sub nom. *Washington* vs. *Glucksberg*, 521 US 702 (1997).

[21]*Quill* vs. *Koppel*, 870 F. Supp. 78 (S.D.N.Y. 1994), rev. sub nom. *Quill* vs. *Vacco*, 80 F3d 716 (2d Cir 1996), rev. 521 US 793 (1997).

[22]Susan M. Wolf, "Pragmatism in the Face of Death: The Role of Facts in the Assisted Suicide Debate," *Minnesota Law Review* 82 (1998): 1063, 1065.

[23]Ibid., 1066.

[24]Ibid., 1067. Sandra Johnson also finds that on key points the Ninth Circuit's decision is not supported by empirical evidence. That court's "confidence in the medical commitment to providing effective pain relief through available means is not supported in currently available data." Johnson, "End-of-Life Decision Making," 33. "The Ninth Circuit's confidence greatly exceeds what

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the empirical data would support" regarding "doctor's interest in and commitment to following the patient's wishes concerning medical treatment at the end of life." Ibid., 34 (citations omitted).

[25]Jessica H. Muller, "Anthropology, Bioethics, and Medicine: A Provocative Trilogy," *Medical Anthropology Quarterly* 8 (1994): 448, 454.

[26]See Kenneth C. Davis, "An Approach to Problems of Evidence in the Administrative Process," *Harvard Law Review* 55 (1942): 364; Davis, "Facts in Lawmaking," *Columbia Law Review* 80 (1980): 931.

[27]*Muller* vs. *Oregon,* 208 US 412 (1907). His "Brandeis brief" recited "extracts [on the ill effects of long hours on female workers] from over ninety reports of committees, bureaus of statistics, commissioners of hygiene, inspectors of factories, both in this country and in Europe," as the Supreme Court noted in ruling in his client's favor.

[28]Alexander M. Capron, "*Daubert* and the Quest for Value-Free 'Scientific Knowledge' in the Courtroom," *University of Richmond Law Review* 30 (1996): 85—discussing *Daubert* vs. *Merrell Dow Pharmaceuticals, Inc.,* 509 US 579 (1993) and *Frye* vs. *United States*, 293 F. 1013 (D.C. Cir 1923).

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Two centuries ago it was said by a court of law that a physician experiments at his peril; if he departs from the accepted method of treatment, he is responsible for any untoward consequence to the patient. Today we are more likely to say that all serious therapy is experimental. The deepened knowledge of complex biological processes, the proliferation of powerful and sensitive drugs and therapies, the range of options in treatment, and the idiosyncrasies of patients' reactions, all make it inevitable that sound medical practice be experimental in a sense that does not contradict the nineteenth-century admonition, but renders it much less meaningful and serviceable as a guide to professional conduct.

Paul A. Freund

From "Introduction to 'Ethical Aspects of Experimentation with Human Subjects'"
Dædalus 98 (2) (Spring 1969)

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